

## **Dementia:**

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**Abstract book** 

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#### PL1-003

## Improving post-diagnosis support and quality of life through innovative education and training

Ms Claire Webster

McGill University, Montreal, Canada. Caregiver Crosswalk Inc., Montreal, Canada

#### **Plenary session**

Plenary 1: Global and national policy landscape

#### **Abstract**

**Background:** There are increasing numbers of persons living with dementia (PLWD) and care partners because of the aging of populations around the world and all healthcare professionals will interact with the PLWD and their care partners at some point in their career. These healthcare professionals will require a working knowledge of the symptoms of dementia, the diagnostic process and principles of management through the various clinical stages. Universities can play a very important role in providing post-diagnosis dementia education and support to the community by ensuring the medical students receive the required training as well as offering educational resources for the PLWD and their care partners. The McGill University Dementia Education Program was founded in 2017 by Claire Webster, a former care partner and dementia care consultant with this aim.

**Methods:** The program offers a comprehensive range of free resources and cutting-edge teaching and learning techniques, including simulation to educate and support persons living with dementia, family and informal care partners, healthcare professionals, medical students and the public at large; a dementia companion guide available in 12 different languages, over 100 educational webinars and podcasts, a dementia activity booklet and 14 bilingual video capsules demonstrating activities to engage people living with dementia, virtual support groups for care partners including young carers, and an online education program.

Since 2020, Claire Webster has become a permanent Faculty Lecturer within McGill University's Faculty of Medicine and Health Sciences for which her talk "Navigating the Journey of Caring for a Person Living with Dementia", which has become mandatory for all first-year medical students.

**Results:** Within only 5 years of its inception, the McGill University Dementia Education Program has received international recognition. The Academic and Medical Directors of the program were selected by Alzheimer's Disease International to write the 2021 and 2022 World Alzheimer's Reports on the interrelated topics of diagnosis and post-diagnosis management.

**Conclusion:** Universities can play a critical support role, bridging academia and community to provide service to society. They can institute community outreach programs that leverage the wealth of expertise within their institution, and they can integrate caregiver awareness and education into their medical school curriculum.



#### PL2-004

## Dementia National Plan in Chile. Projections and challenges seven years after its implementation

#### Mr Francisco Cubillos

Department of Mental Health, Santiago, Chile

#### **Plenary session**

**Plenary 2:** The imperatives of diagnosis and treatment

#### **Abstract**

Dementias, such as Alzheimer's disease and other neurocognitive disorders, represent a growing challenge in our contemporary society. The aging of the population, combined with the increase in life expectancy, has led to a significant increase in the incidence of these diseases and this has brought with it important challenges for public health. That is why the Ministry of Health of Chile has become aware that the treatment of dementia is not only a personal or family matter, but a public health problem that requires a collective and coordinated response by the health and social care network. In this paper we will review the response of the state of Chile to this health situation, through the National Dementia Plan, created in 2017, where a coordinated, intersectoral and comprehensive response is offered for people with dementia and their supporting environment, in addition to raising a path to continue in the future. However, seven years after its beginning, it is necessary to review this plan to allow its continuity. The purpose of this presentation is to comment on the achievements and challenges that this public health policy has obtained.



#### PL3-002

## Implementing anti-stigma initiatives to build dementia-friendly communities in low-resource settings: Experiences from Brazil and Kenya

#### Dr Déborah Oliveira

Universidad Andrés Bello Faculty of Nursing, Santiago, Chile

#### **Plenary session**

Plenary 3: World Alzheimer's Month and Dementia Friendly Communities: urgent priorities

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Fighting stigma and discrimination directed at people living with dementia is key to raising awareness and to building dementia-friendly communities. Although the majority of people with dementia reside in low- and middle-income countries, most of the evidence around dementia-related stigma comes from high-income nations. Healthcare resources and capacity building initiatives are limited in low-resource settings, making anti-stigma strategies involving community healthcare workers a potentially cost-effective and scalable option. In this presentation, I will detail the development and evaluation processes of two anti-stigma initiatives targeting community health workers: one from Kenya and another from Brazil. I will show the preliminary qualitative and quantitative findings of each intervention, contextualising these in relation to both the current policy landscape related to dementia, as well as the community understandings of dementia in the two countries. I will briefly discuss the potential benefits of scaling up such interventions within and beyond the two countries, whilst alluding to the factors that could facilitate or hinder this, in line with WHO's toolkit for dementia-friendly initiatives. I will finalise the presentation with key recommendations for future work in this area.



#### PL4-001

## Strengthening health and social care systems to support people living with dementia from diverse Background:s: research and inclusion approaches

Dr Lee-Fay Low

University of Sydney, Sydney, Australia

#### **Plenary session**

Plenary 4: Solutions and challenges in strengthening care support

#### **Topic**

Support for dementia carers

#### **Abstract**

People with dementia from culturally and linguistically diverse (CALD) backgrounds tend to get diagnosed later and receive or use less treatments and services than people from non-diverse backgrounds. Public dementia stigma may be higher in some CALD communities compared to WEIRD groups (Western, Educated, Industrialized, Rich, and Democratic). Systemic and individual discrimination and cultural differences underpin these inequities. This presentation will discuss the importance of involving diverse groups in dementia research to inform health systems improvement. We will explore challenges in terminology (e.g. race, ethnicity, culture), group categorisation (e.g. by country of birth, language spoken, identified ethnicity), and research measurement (e.g. neuropsychological tests, psychological scales). We will explore issues of equity and equality, diverse rather than representative samples, translation and interpreting and cultural adaptation of psychosocial dementia interventions.



#### PL4-002

## Successful dissemination of proven effective combined support for people with dementia and their carers: the Meeting Centres Support Programme

#### **Prof Rose-Marie Dröes**

Amsterdam University Medical Centres, Amsterdam, Netherlands

#### **Plenary session**

Plenary 4: Solutions and challenges in strengthening care support

#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

For decades, we have known that combined programmes providing tailored support to people living with dementia and their carers are more effective than single interventions. However, adoption and dissemination of such programmes is not self-evident and can be promoted or hindered by many factors at micro, meso and macro levels.

The combined Meeting Centres Support Programme (MCSP) for people with dementia and their informal carers was successfully disseminated in the Netherlands following participatory development, pilot projects, impact evaluation and implementation studies (1993-2003), and then adaptively implemented in other countries in Europe and beyond since 2014.

MCSP aims to support people in a person-centred way to live well with dementia. Meeting Centres are socially integrated into the neighbourhood, in easily accessible community locations. A small staff and volunteers offer a 'club' for 10-15 people with dementia, several days per week, with a range of psychosocial interventions, recreational, creative and movement activities tailored to the wishes, needs and abilities of participants, and peer support groups and informative meetings for their carers. Individual consultations and group outings are available for both. The centres collaborate with regional care and welfare organisations and professionals. Over the past 30 years, controlled studies demonstrated benefits of MCSP compared with usual daycare, without carer support programmes, on quality of life, behaviour and mood of people with dementia, carers' sense of competence, and postponement of nursing home admission.

In 2018, the international MeetingDem Network (www.meetingdem.eu) was established to encourage further dissemination of MCSP in Europe and beyond, exchange knowledge and experiences, and facilitate collaboration in post-diagnostic psychosocial research. And with success: 204 Meeting Centres are currently available in the Netherlands, and more than 100 centres in other countries in Europe, Africa, Asia, and South America. This lecture will discuss dissemination and implementation strategies and activities that have contributed to this successful spread.



#### PL4-004

### A vision for a world where no younger family walks alone with dementia

**Ms Diana Cose** 

Lorenzo's House, Chicago, USA

#### **Plenary session**

Plenary 4: Solutions and challenges in strengthening care support

#### **Abstract**

Their sons were nine and eleven when brain change showed up in their home. She calls younger-onset a 'diagnosis of the family' - because of its far reaching impact, especially on kids. After Diana's husband, Lorenzo was diagnosed with younger-onset Alzheimer's she learned that younger families living with dementia are unseen, misunderstood, and under-resourced. She leveraged her proven entrepreneurial background and set out to solve this societal problem, founding Lorenzo's House in 2021. Today, Lorenzo's House is shifting the narrative for younger families worldwide; curing isolation, building community and driving dementia justice. Diana shares poignant personal reflections, and unfolds her vision for a world where no younger family walks alone with dementia, instead united and in the light.



#### PL5-001

#### A public health approach to dementia risk reduction

#### **Dr Sebastian Walsh**

University of Cambridge, Cambridge, United Kingdom

#### **Plenary session**

**Plenary 5:** Risk reduction and prevention: the latest research and the challenges of bringing new messages to the broader public

#### **Abstract**

**Aims:** To define, summarise existing evidence for, and build the evidence base for population-level approaches to dementia risk reduction.

**Background:** Evidence from high-income countries shows a reduction in the age-specific incidence of dementia over recent decades. This suggests that the risk of dementia in the population can be reduced. Recent evidence has even suggested that greater prosperity and increased health behaviours across the lifecourse can lead to an absolute reduction in years lived with dementia despite greater life expectancy ('compression of morbidity'). This suggests that, though ageing of populations is forecast to lead to an increase in dementia prevalence, this could be mitigated at least in part by efforts to reduce dementia risk across the population.

**Approach:** Reducing dementia risk can be achieved by action on established modifiable risk factors. Broadly, this can be done either by encouraging individuals to understand and lower their own risk, or by changing the societies and environments in which people live and age such that they are more conducive to brain health. There are concerns that individual-level approaches will be ineffective and/or widen dementia inequalities, whilst the latter approach has received insufficient attention from the dementia research community.

**Research:** Mixed methods research including semi-structured interviews with policymakers in England to explore perspectives on, and barriers and facilitators to, individual- and population-level approaches to dementia risk reduction; reviews of population-level intervention theory, existing dementia risk reduction literature, and empirical population-level interventional evidence for action on dementia's modifiable risk factors; quantitative analysis of a population-based cohort in England to investigate whether Rose's prevention paradox and the compression of morbidity hypothesis can be empirically demonstrated for dementia; and policy analysis to investigate the focus (individual- or population-level) and agency of existing dementia risk reduction policy in England.



#### PL5-002

#### A Multi-National Collaboration to Assess the Feasibility and Sustainability of Implementing Multimodal Brain Health Promotion Strategies in Sub-Saharan Africa (The AFRICA-FINGERS Project)

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#### **Plenary session**

**Plenary 5:** Risk reduction and prevention: the latest research and the challenges of bringing new messages to the broader public

#### **Abstract**

**Background:** Dementia prevalence in Sub-Saharan-Africa (SSA) is rising; however, scant research examines the impact of lifestyle factor changes on dementia risk. The landmark Finnish-Geriatric-Intervention-Study-to-Prevent-Cognitive-Impairment-and-Disability (FINGER) demonstrated improvements in cognition and health outcomes 2-years post-intervention. This approach is being adapted and tested internationally, within the World-Wide FINGERS (WW-FINGERS) network. Yet no FINGER-based trials have adopted systematic community-based culturally sensitive methods to test feasibility or efficacy in Sub-Saharan Africa (SSA), especially across countries, with highest estimates of projected dementia prevalence. Overcoming these gaps, we have initiated The AFRICA FINGERS Program: a multi-national collaboration towards brain health promotion in SSA, leveraging expertise from WW-FINGERS, Davos Alzheimer's Collaborative (DAC), Alzheimer's Disease International (ADI) and Global-Brain-Health-Institute (GBHI) partners alongside the Global-Dementia-Prevention-Program (GloDePP) platform. AFRICA-FINGERS represents the first attempt to coordinate and implement culturally informed multidomain dementia-risk reduction interventions across SSA, with sustainability goals embedded within the initiative.

**Methods:** AFRICA-FINGERS is a multinational brain health promotion initiative (at-risk for dementia adults >50 years, n=600) set within established academic research infrastructures with already-phenotyped cohorts in both urban and rural areas within Kenya and Nigeria initially as Vanguard sites. The programme will be nested within the WW-FINGERS framework and will work with in-country stakeholders and project partners to strategically execute effective, culturally informed, risk reduction trials and health systems implementation programs.

As a first step, the project will leverage existing relationships with established in-country Community Advisory Boards (CAB) comprising dementia patients and caregivers, dementia researchers and healthcare workers, policy makers and local community members (n=10/group). Focus group discussions (FGDs), in-depth interviews (IDI) and in-home observations will be conducted to explore contextual experiences around dementia prevention, knowledge of risk factors; gain feedback and input on adaptations for planned intervention modalities (physical/social activity, healthy diet, cognitive training, and vascular/metabolic risk monitoring), and identify priority needs for dementia prevention and care in these settings. Systematic thematic analysis of FGD and IDI transcripts will be employed, and AFRICA-FINGER intervention protocol co-developed.

**Results:** Experimental approach and strategy for the AFRICA-FINGERS project, and its integration within the WWFINGERS framework will be presented.



**Conclusions:** With a growing elderly population, there is an urgent need to identify facilitators and barriers and investigate the effectiveness of culturally appropriate clinical research paradigms for dementia prevention in Africa that can be translated to similar demographics globally. The study provides novel insights into risk reduction strategies for indigenous Africans and develops the first culturally appropriate dementia prevention protocol in SSA to support cognitive and physical health. Results will provide evidence-based prevention strategies to support implementation of regional dementia research and early identification pathways. Study methodologies will be adapted and tested in partner sites across Sub-Saharan Africa, to gain a better understanding of the ethnographic and clinical complexities of dementia prevention in Africa.



#### PL6-002

#### Precision medicine in dementia

#### Dr Pascual Sánchez

Fundación CIEN, Madrid, Spain

#### **Plenary session**

Plenary 6: Data, research, innovation and therapies: New thinking, new directions

#### **Abstract**

Clinicopathological studies reveal that approximately one-third of clinical diagnoses in dementia patients are inaccurate. Utilizing core biomarkers for Alzheimer's disease (AD), such as cerebrospinal fluid (CSF) analysis and positron emission tomography (PET) studies, can significantly reduce this error rate. Despite the acknowledged importance of AD core biomarkers, various studies indicate that their adoption by clinicians remains minimal. In the emerging era of disease-modifying treatments, precise diagnosis becomes imperative. However, core AD biomarkers have limitations, including invasiveness and cost. Consequently, efforts are underway to develop more scalable biomarkers. Before integrating these biomarkers into clinical practice, further evidence is essential, particularly from large studies that encompass diverse clinical scenarios. SCAP.AD represents a nationwide initiative aimed at validating several new biomarkers within the Spanish population. Two sizable cohorts are currently being recruited to validate plasma, genetic, and digital biomarkers.



#### PL6-003

## The Alzheimer's Association Strategy for Increasing Research Funding, Then Managing and Prioritizing Projects

Dr Joanne Pike

Alzheimer's Association, Chicago, USA. Alzheimer's Impact Movement, Washington, USA

#### **Plenary session**

Plenary 6: Data, research, innovation and therapies: New thinking, new directions

#### **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

Since 2012, when the United States first issued a National Alzheimer's Plan, annual U.S. government funding for research on Alzheimer's and related dementias has increased more than 700% to more than 3.7 billion USD in 2023. To accomplish this significant increase, the Alzheimer's Association embarked on and led a multi-pronged strategy. It started with the creation of the National Plan and subsequent legislation to require the scientists at the National Institutes of Health (NIH) to bypass normal budget procedures to inform Congress directly how much funding for Alzheimer's research was needed. It involved cultivating champions within Congress and mobilizing tens of thousands of grassroots advocates to lobby their members of Congress for more Alzheimer's research. And, it required developing messages and telling stories that would appeal to all sides of the ideological spectrum – both on the campaign trail and in the halls of Congress.

At the same time, the Alzheimer's Association significantly increased our direct investment in research to over \$100 million in 2023. This includes broadening funded projects across the entire spectrum of research in all diseases that cause dementia, bringing together researchers in all corners of the world and providing opportunities that spur innovation and collaboration. Today, the Association has active and committed funding in 56 countries, 1100+ projects totaling over USD\$405 million. Bringing together the global scientific community, the Association's convening continues to bridge all areas of scientific discovery and provide important opportunities for access to the latest in scientific conversations in all corners of the world. Further, the Association's professional society, ISTAART, enables collaboration and cooperation in specific areas of interest through grassroot opportunities to elevate focused discussions.

In summary, through advocacy and direct organizational investment, the Alzheimer's Association has spurred significant increases in research funding for the disease in the U.S.



### **Exploring Hearing Loss as a Risk Factor for Parkinson's Disease Dementia**

**Dr Megan Rose Readman**<sup>1,2,3</sup>, Dr Clarissa Giebel<sup>1,2</sup>, Dr Dalia Tsimpida<sup>4,5</sup>, Mr Ian Fairman<sup>2</sup>, Prof Christopher J Plack<sup>3,6</sup>

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** Evidence has implicated hearing loss (HL) as a, potentially modifiable, risk factor for dementia. Specifically, mild HL almost doubles dementia risk; moderate HL triples dementia risk; and severe HL increases dementia risk almost five times. Whilst the evidence is compelling, most studies consider an 'all-cause' dementia outcome. However, dementia is an umbrella term used to categorise multiple, symptomatically similar, conditions. Thus, an 'all-cause' category does not elucidate whether HL is a universal risk factor across different dementia types. The present study therefore aims to investigate whether HL is a risk factor specifically for Parkinson's dementia.

**Method:** An age-adjusted survival model analysis of the UK Biobank, a prospective cohort study containing biomedical and socioeconomic data pertaining to half million UK residents (525 Parkinson's dementia cases), will be conducted. This study was co-designed, and is being conducted, in collaboration with people living with Parkinson's and HL, and carers of people living with Parkinson's dementia.

**Results:** The present analysis is due to be complete by November 2023. Therefore, these findings will be presented for the first time at ADI.

**Conclusions:** These findings may have important implications for dementia care. Specifically, if HL is a risk factor for Parkinson's dementia this may reinforce current debates towards considering residual HL in dementia diagnostic assessments and the involvement of hearing services in dementia care. Conversely, if HL is not a risk factor for Parkinson's dementia this may indicate that we cannot apply a blanket approach when considering the role of hearing health in dementia care.

#### **Keywords**

Hearing Loss, Parkinson's Dementia, Risk Factor





## Risk factors for Dementia in Mexico. Prevalence, burden of disease and three decade trajectories.

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aim:** To analyse prevalence of dementia risk factors in Mexico and their associated burden of disease from 1990 to 2022, by sex and age groups. In addition, to estimate the percentage of disability adjusted life years due to dementia by risk as a proportion of the DALYs by all causes for adults 60 years and older.

**Methods:** Estimated prevalence of risk factors (education, smoking, diabetes, hypertension, obesity) using the National Health and Nutrition Survey (2006, 2012, 2018, 2022), a cross-sectional repeated nationally-representative survey of adults 20 years and older. We use the Global Burden of Disease (IHME) data base (1990 to 2022) to explore trajectories and estimate total disability adjusted life years (DALYs) due to dementia by risk and as a proportion of DALYs for all causes in adults 60 years and older.

**Results:** Prevalence rates for overweight/obesity and diabetes have steadily increased, while for some age groups hypertension rates have somehow stabilised, likely as a result of prevention and management strategies. Looking at trajectories of prevalence of risk factors and their impact in the global burden of disease, we can see that smoking rates have decreased in the past decade, however, data show that smoking, compared to high blood glucose and high body-mass index represent the highest percentage of DALYs due to dementia.

**Conclusion:** In-light of recent and growing evidence on the fact that up to 40% of dementia cases could be prevented by reducing some risk factors that are modifiable, it is clear that countries as Mexico should strongly work on reducing these in order to prevent an exponential growth in dementia cases. The healthcare system should resume past efforts to tackle smoking, regulate e-smoking strongly, and increase public infrastructure to support physical activity and exercise for all, given their largest impact on the burden of disease.

#### **Keywords**

Burden of disease, dementia risk factors, disability adjusted life years (DALYs), Mexico



#### Does the relative risk of potentially modifiable risk factors for dementia vary between ethnic groups within one country? A retrospective cohort study using routinely collected health data in Aotearoa New Zealand

**Dr Etuini Ma'u**<sup>1</sup>, Dr Sarah Cullum<sup>1</sup>, Dr Gary Cheung<sup>1</sup>, Dr Claudia Rivera-Rodriguez<sup>1</sup>, Dr Jade Tamatea<sup>1</sup>, Prof Gill Livingston<sup>2</sup>, Dr Naaheed Mukadam<sup>2</sup>

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Background:** The prevention potential for dementia in Aotearoa New Zealand (AoNZ) is high. While the relative contribution of individual risk factors for dementia in AoNZ varies by ethnic group due to differential risk factor prevalence, it is not known whether ethnicity is associated with a differential relative risk. We aimed to calculate the relative risk of ten risk factors for dementia (education, smoking, obesity, hypertension, air pollution, social isolation, diabetes, depression, alcohol, physical inactivity) in the four largest ethnic groupings (European, Māori, Pacific peoples, Asian) and to identify whether relative risk varied across the ethnic groups within an AoNZ cohort.

**Methods:** This retrospective cohort study linked risk factors for dementia in the New Zealand Health Survey with seven administrative health datasets to identify incident cases of dementia by prioritised ethnicity. Cox regression models were used to calculate the hazard ratio of dementia for each of the risk factors, and to explore potential interaction effects between each of the risk factors and ethnicity (after adjusting for age, sex, and deprivation.)

**Results:** The hazard ratios for all risk factors except hypertension (p=0.770), alcohol (p=0.087) and air pollution (p=0.153) were significant for dementia risk. Of these seven significant factors, all except obesity (HR 0.85, 95% CI 0.76-0.94) were associated with an 1.13-1.55 higher hazard ratio of dementia. Despite differences in prevalence and therefore risk impact, there were no significant interaction effects of ethnicity for each of the risk factors in the fully adjusted model.

**Conclusions:** Ethnicity was not associated with a higher hazard of dementia for any risk factors, suggesting differences in prevention potential are primarily explained by differential risk factor prevalence between ethnic groups in AoNZ. Public health strategies addressing these risk factors and their social determinants must be tailored and prioritised for the ethnic populations at most risk.

#### **Keywords**

dementia, risk factors, relative risk, New Zealand, ethnicity, Maori, Pacific peoples





# Process Evaluation of APPLE-Tree (Active Prevention in People at risk of dementia through Lifestyle bEhaviour Change and Technology to build REsiliEnce), a Dementia-Prevention Study focused on Health and Lifestyle changes

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** To conduct a process evaluation embedded within the APPLE-Tree dementia-prevention trial, which tested an intervention focused on changing health and lifestyle behaviour among people aged 60+. We aimed to investigate how it might have supported participants to meet personalised behavioural and lifestyle goals.

**Methods:** We interviewed participants, facilitators and study partners (family members or friends) purposively selected from APPLE-Tree participants who have Subjective Cognitive Decline (SCD) or Mild Cognitive Impairment (MCI), allocated to the intervention arm. The intervention involved weekly virtual groups sessions with facilitators for 6 months, with individual goal-setting phone calls every 2 weeks, and monthly 'catch-up' sessions from 6 to 12 months. We recruited from 4 groups and, additionally, participants from minority ethnic groups and who had withdrawn. Interviews were semi-structured using topic guides. They were thematically analysed in NVivo, inductively and deductively, drawing on concepts from the COM-B model (Capability, Opportunity, and Motivation leading to Behavioural change). We included records of aims set during goals calls and attendance data in the analysis.

**Results:** We interviewed 19 participants who participated in the intervention, 6 participants who had withdrawn, 14 facilitators and 3 study partners. Themes were generated around experiences of engagement, with connections with other participants and relationships with facilitators helping to promote engagement and healthy behaviours and reduce isolation; increased Reflective Motivation (thought processes such as plans and evaluations); increased Capability (knowledge about healthy behaviours); and changes in habits, corresponding with Automatic Motivation.

**Conclusion:** The intervention helped participants to reflect, plan, evaluate and increase their knowledge, leading to changes in habits. The main trial results report in 2025.

This project (ES/S010408/1) was funded jointly by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). ESRC is part of UK Research and Innovation.

#### **Keywords**

Process Evaluation, Dementia-Prevention, Intervention, Health, Lifestyle, Randomised controlled trial



#### Neuroinflammation-induced by interaction of Microbiota on the Gut-Brain axis in Alzheimer's disease: An insight to etiopathogenesis and disease management.

#### Mr Benjamin Temidayo Adebisi

Institute of Anatomy, Cell Biology, Brain and Neurodegeneration., Osogbo, Nigeria

#### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

**Aim:** The exact course of Alzheimer's disease remained incompletely unravelled, although studies have linked genetics, environmental causes and lifestyles as risk factors of the age-linked neurodegenerative disease; a recent study has been trying to connect the nature of bacteria in the gastrointestinal tract with patients suffering from the disease. Thus, the research is imperative to elucidate how the microbiota in the gut has been responsible for the etiopathogenesis of Alzheimer's disease, diagnosis and plausibly look into suggesting probiotics to encourage good bacteria in the gut in order to alleviate symptoms of sufferers.

**Methods:** Reviews of research articles discussing the gut-brain axis, role of microbiome in neuroinflammation, beta amyloid protein aggregation and neurodegeneration, in patients with Alzheimer's disease, were instrumental to connect the link of the indictment of gut bacterial to disease cause and progression.

**Results:** Disruptions of the microbiota have potential; to drive immune dysfunction. the bacterial lipopolysaccharide, LPS, plays a major role in inflammatory process in neurodegenerative diseases. LPS results in neuroinflammation by activation of proinflammatory biomarkers; this process leads to astrogliosis, synaptic dysfunction and microglia activation. The cumulative effects of these include calcium ion mishandling. glutamate excitotoxicity, mitochondrial dysfunction, impaired proteostasis and beta amyloid misfolding, characteristic of the disease.

**Conclusion:** It is clear that the nature and volume of certain bacterial might be a biomarker in early diagnosis of Alzheimer's disease and the use of probiotics and nutrition mitigating such bacterial, while promoting the rather good bacterial might be the next line of action in the disease management.

#### **Keywords**

Microbiota, Neuroinflammation, Neurodegeneration



## Dementia Trials Ireland, a HRB Clinical Trial Network – increasing capacity and capability to deliver clinical trials for dementia in Ireland.

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#### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

**Introduction:** Fewer than 0.5% of people with dementia (PwD) participate in research in Ireland. Dementia Trials Ireland (DTI), a new national network, aims to triple national dementia trial activity and to enable research opportunities for PwD and carers. DTI comprises a range of expertise to develop a dementia trials' portfolio spanning the life course of dementia and dementia subtypes. It includes clinical academics, dementia researchers and third-sector partners.

**Methods:** DTI comprises four workstreams:

- Stream 1, 'Trial Readiness': supports clinical workforce development through professional mentorship and research funding awards.
- Stream 2, 'Trial Development': fosters funding proposals via inter-disciplinary collaborations and trial methodology projects.
- Stream 3, 'Trial Delivery': ensures timely, on target, high quality trial delivery.
- Stream 4, 'Participant and Public Involvement': crosscuts DTI workstreams, lived dementia experience informs all stages of work, from conception to dissemination.

**Results:** Key outputs at 18 months:

- Increased accessibility to dementia-trials participation.
- A developing trials' portfolio (industry RCT & investigator-led studies) with the network's first global RCT delivered on time & to target.
- National trial site feasibility review to establish an evidence base for future network and policy development.
- National clinical workforce development and trial delivery training events.
- Trial methodology studies, i.e., core outcome set (COS) development, research priority setting partnerships for dementia, scoping 'research readiness' and 'care as usual' in long term care in Ireland.

**Conclusion:** DTI, in taking a 'needs focused, end user informed' approach to infrastructure and capacity development for dementia trials is positioning Ireland internationally to deliver impactful, high quality, dementia trials. This work is supported by the Health Research Board [HRB DTI CTN-2021-003].

#### **Keywords**

Dementia, Clinical Trials, Ireland, Capacity, Infrastructure, Participation, Treatment, PPI



## 24-month topline results from Phase 3 LUCIDITY trial in AD show combined disease-modifying and symptomatic activity for hydromethylthionine mesylate (HMTM)

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#### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

**Background:.** HMTM is an oral treatment targeting pathological tau aggregation. It also has secondary tau-independent activity which increases acetylcholine levels in hippocampus.

**Methods.** LUCIDITY is a Phase 3 trial in MCI-AD and mild to moderate AD in an amyloid-PET positive population. An initial 12-month randomised double-blind period compared HMTM at 16 (target dose) and 8 mg/day with methylthioninium chloride (MTC) 4 mg twice weekly as a blinded control. After 12 months, all participants received 16 mg/day HMTM in a modified delayed-start design. Change on ADAS-cog11 and ADCS-ADL23 over 12 months were coprimary clinical outcomes and change in plasma neurofilament light chain (NfL) concentration was the prespecified blood biomarker outcome to measure progression of neurodegeneration. Various subgroup analyses were pre-specified including split by diagnosis.

**Results:** Participant numbers at randomisation, 12 months and 24 months were: HMTM 16 mg/day (252/191/162), 8 mg/day (80/57/39) and control (266/207/170). HMTM 16 mg/day produced a statistically significant 95% reduction in change in NfL as randomised (p=0.0278) compared to control. Overall cognitive decline did not differ between arms but was significantly less than closely matched real-world populations over 12 and 24 months. Relative to baseline, MCI-AD subjects receiving 16 mg/day showed statistically significant cognitive improvement sustained over 18 months and no decline at 24 months. Control MCI-AD subjects had transient symptomatic benefit at 6 months, but thereafter declined significantly. Control subjects with AD also experienced initial symptomatic exposure-dependent cognitive benefit. The safety profile was excellent with no ARIA. Long-term safety is supported by a long-standing Expanded Access Program.

**Conclusion.** HMTM combines slowing of neurodegeneration and symptomatic benefit. It is an accessible, safe, oral treatment for MCI-AD to mild/ moderate AD which could be delivered with minimal patient, physician, and healthcare system burden worldwide.

#### **Keywords**

Alzheimer's treatment, mild cognitive impairment (MCI), Phase 3, neurofilament light chain (NfL), plasma biomarkers



### Rethinking Alzheimer's Disease - Widening the View on Pathogenetic Factors

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#### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

Alzheimer's Disease (AD) is a multifactorial/multigenetic highly complex age-associated disorder. Despite intensive research efforts - especially in the last three decades - and a vast amount of molecular knowledge on plaque-associated amyloid beta (and tangle-associated tau) protein, the exact causes of this brain disease still remain elusive. Even though, recently, novel anti-amyloid antibodies have displayed minor beneficial effects in clinical trials, to date, no convincing therapies are available. Research may have focused on AD as 'plaques-and-tangles-disease' too strongly, blinding out additional pathogenetic factors and alternative pathways. Today, the AD research field appears strongly divided. One part primarily focuses on research driven by the 'amyloid-cascade-hypothesis' introduced 30 years ago seeing amyloid beta as culprit and initial disease trigger. The other part has alternative views on how AD could develop beyond amyloid, some were introduced many years ago, but were not adequately followed such as the role of oxidative stress, mitochondrial disturbance, and of misbalances of proteostasis/autophagy and lipid metabolism (and others). Moreover, due to the high number of identified GWAS-based genetic risk factors, AD appears to be highly individual. The particular genetic risk factor configuration may determine the individual's brain resilience to adapt to challenges (e.g. brain-trauma, infections, inflammations, metabolic challenges), defining the onset of neurodegeneration during aging. Consequently, AD could be a prime candidate for a 'personalized medicine' therapy approach. In addition, a deeper understanding of the (individual) neuronal factors and mechanisms of vulnerability, would allow to encounter targetable pathways for AD therapy and prevention. To reach all this, a significant 'paradigm shift' in AD research beyond amyloid is indispensable, a shift that includes the integration of various partly overlooked alternative disease hypotheses (Behl, 2023 doi.org/10.1007/978-3-031-31570-1).

#### **Keywords**

Alzheimer's Disease causes, alternative hypotheses, personalized medicine, paradigm shift



## Charting the Dementia Journey: Supporting the Empowerment of People Living with Dementia to Live Well through Dementia Self-Management

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#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

For people diagnosed with dementia, it is important to know that people can and do live well with dementia, especially when they develop personalized strategies to manage their condition and proactively support their well-being. As such, members of Dementia Friendly Nevada - including six advisors who are living well with various types of dementia—leveraged the principles of chronic disease self-management to develop a Dementia Self-Management Guidebook that encourages people recently diagnosed with dementia to engage family, friends, and a range of healthcare professionals as "support partners" in the self-management process, acknowledging that we are all both independent and interdependent. This session explores the Guidebook: an innovative, freely available resource designed by and for people living with dementia to maximize accessibility and customizability. The session will also share findings from a program evaluation of recent in-person and virtual pilots of an eight-week Dementia Self-Management Program that uses the Guidebook to engage people living with mild to moderate dementia in a group setting. The session will explore the development of the Guidebook and Program and will unpack the complexities and potential of working in authentic partnership with people living with dementia according to a human-centered design process. The session will also feature an opportunity to hear directly from the six Guidebook advisors living with dementia about their experience as partners on this project, the personalized strategies they have developed to live well, and how they hope to see the Guidebook and Program used to support the well-being of people living with dementia globally.

#### **Keywords**

Dementia, Self-Management, Support, Resource, Self-Advocacy, Brain Health, Well-Being



## Nutritional Status and Eating Behaviors in People with Dementia in Nursing Home Settings: A Cross-Sectional Observational Study

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#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

**Aims:** Cognitive decline in individuals with dementia often leads to altered eating behaviors', increasing their vulnerability to malnutrition, which, in turn, correlates with extended hospitalization and elevated mortality rates. Considering the heightened malnutrition risk among dementia residents in nursing homes, this study aims to comprehensively evaluate their nutritional status and eating behaviors.

**Methods:** This cross-sectional observational study collected data on mealtime challenges and the nutritional status of 51 dementia residents in nursing home settings. Data collection tools included the Feeding Difficulty Index, Eating Encouragement for Residents with Dementia, nurses' feeding skills assessment, Optimizing Care in the Dining Room Audit Tool, and Mini Nutritional Assessment Short Form

**Results:** A total of 51 dementia residents were recruited, with a median age of 85.2 years and a Feeding Difficulty Index averaging 9.4. Their average nursing home residency duration was 4.5 years, with a mean total feeding time of 27.8 minutes during meals. Alarmingly, only 2.5% of participants had a normal nutritional status, while a significant 78.5% were malnourished. All participants required some level of mealtime assistance. Notably, residents with higher Feeding Difficulty Index scores tended to have longer total feeding times. Surprisingly, a limited percentage of nurses consistently employed specialized feeding skills: approximately 12% used multisensory cueing, 15% practiced task simplification and sequencing, and less than 10% employed techniques such as mirroring, the hand-over-hand approach, and bridging.

**Conclusion:** Tailored training for nursing staff is vital to mitigate malnutrition risk among dementia residents in nursing homes. These programs should enhance feeding skills, address eating behavior issues, and overcome mealtime challenges, thus improving residents' nutritional well-being and quality of life. The study's clinical significance lies in its potential to identify and rectify eating behavior issues and mealtime difficulties, ultimately enhancing the nutritional well-being and overall quality of life for this vulnerable population.

#### **Keywords**

Eating behaviours, malnutrition, people living with dementia, nursing home



## Who should decide? Co-development and Application of a Priority-Setting Approach for Dementia Care Research

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#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

The voice of people living with dementia (PLwD) is paramount in dementia care research. It is increasingly common for PLwD to be involved in supporting funding applications, shaping study design, and contributing to dissemination (e.g., Miah et al., 2020). However, PLwD often become involved after researchers have already determined the overall topic or area of research. While various approaches, tools, and methods have been developed for setting priorities in health and social care research (e.g., Yoshida, 2016), few have been successfully applied in priority-setting work with people living with dementia.

The aim of our priority-setting work was to exclusively amplify the perspectives of PLwD. While the opinions of all stakeholders involved in dementia care are important, there has been a tendency for carer and service provider perspectives to considerably outnumber those of PLwD when research priorities are set (e.g., Kelly et al., 2015). Our work, therefore, included only people living with dementia.

To ensure that priority-setting methods are inclusive and accessible, we adopted a three-step approach. Our work began with a collaboration between a university-based researcher, a co-researcher living with dementia, and their volunteer supporter. This ensured that all aspects of the work were informed by lived experience.

Next, a 'working group' of people living with dementia came together to develop the prioritization approach. This group focused on determining how best to facilitate a larger group of PLwD in setting research priorities for dementia care. Finally, the co-produced approach was used during priority-setting events and included ranking priorities by perceived importance.

In this presentation, we will share both the priority-setting approach co-produced with people living with dementia and the priorities themselves. Additionally, we will discuss our reflections on the collaboration process and share lessons learned that may benefit others considering research priority-setting with PLwD.

#### **Keywords**

Dementia care research; Priority-setting; Co-production; Lived experience;



### Emotional experience and coping strategies used by people living with Alzheimer after diagnosis

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#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

**Introduction:** A diagnosis of a major cognitive disorder due to Alzheimer (MCD-AD) constitutes a significant life change for those affected. To face the feelings that accompany this moment, coping strategies are required. A better understanding of the subjective emotional experience of people living with Alzheimer is needed to propose interventions adapted to their specific needs.

**Aims:** (1) Gaining a better understanding of the individual emotional experience after an MCD-AD diagnosis; (2) exploring the coping strategies used to face it.

**Method:** A qualitative exploratory design was engaged. Semi-structured interviews were conducted with ten French-speaking persons aged over 70, recently diagnosed with a mild MCD-AD. They were recruited from a cognitive clinic in Canada; selection was based on specific criteria. We applied interpretative phenomenological analysis to the transcribed data. Rigor was based on authenticity, reflexivity, and information power.

**Results:** Participants experienced either choc or denial after diagnosis, but also incomprehension regarding communication within the healthcare system. They engaged in an oscillatory process between their past life memories and current experiences. This enabled them to cope with their undesired emotions and give new meaning to their existence. Coping strategies contributed to maintain autonomy and quality of life. Firstly, the participants experienced a range of undesired emotions, which they tended either to accept, to diminish, suppress or avoid. Some participants adopted more adaptive strategies that gave them a sense of self-determination, power over their lives and hope. Others used less adaptive strategies, such as avoidance and withdrawal from their environment and relationships.

**Conclusion:** These results shed new and deep insight into individual differences in the emotional experience and coping strategies used after a diagnosis of MCD-AD. This new understanding can be used to improve individual accompaniment and intervention during this period of change.

#### **Keywords**

emotional experience, coping strategies, life change, quality of life, self-determination, accompaniment, interpretative phenomenological analysis



## Multiple limbic proteinopathies correlate to psychotic and hyperactive behavioural symptoms: data from the Abbiategrasso Brain Bank.

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

#### **Abstract**

**Aim:** Psychotic and hyperactive behavioural symptoms are the most considerable challenges in the clinical and therapeutic management of people living with dementia. The limbic system is primarily responsible for emotional processes strictly related to behaviour, and the presence of neuroinflammation could exacerbate behavioural symptoms. In our series of pathologically defined dementias, we investigate the correlation of multiple limbic lesions with the aforementioned behavioural symptoms and microglial activation in specific limbic regions.

**Methods:** Twenty-four people diagnosed with dementia from the Abbiategrasso Brain Bank underwent serial neurological and neuropsychological evaluations. At death, they all had a diagnosis of major neurocognitive disorder. According to the donation program, their brains underwent a complete vascular and degenerative neuropathological characterization. Further, microglial activation was assessed in four limbic regions (hippocampus, amygdala, gyrus cinguli, orbitofrontal cortex) through a semi-quantitative method. The Fisher's exact test and the Mann-Whitney test were used for statistical analysis.

**Results:** Clinical diagnosis includes Alzheimer's Disease (AD; n=10), multiple aetiologies (n=8), Lewy body disease (n=2), vascular dementia (n=2) and frontotemporal lobar degeneration (n=2). Additional unexpected neuropathology was found in 19 cases, including Lewy Type Synucleinopathy (LTS) and TDP-43 pathology (TDP). Sixteen cases had psychotic and hyperactive behavioural symptoms; 12 of them exhibited additive limbic pathology (1 LTS; 8 TDP-43; 3 TDP-43/LTS). The presence of multiple limbic proteinopathies (LTS and/or TDP-43 pathology) significantly correlates with psychotic and hyperactive symptoms (p=0.032), the latter also significantly correlates with microglial activation in the dentate gyrus, amygdala and orbitofrontal cortex. Moreover, additive limbic pathologies significantly correlate with microglial activation in the hippocampus.

**Conclusions:** Frequently, limbic LTS and TDP-43 lesions are concomitant suggesting a possible synergistic role of these proteinopathies, promoting neuroinflammation, causing limbic dysfunction and influencing the clinical phenotype.

#### **Keywords**

psychotic, hyperactive, limbic system, Lewy Type Synucleinopathy, TDP-43 pathology, microglial activation



## Predicting dementia diagnosis from cognitive footprints in hospital records among Chinese older adults: A 19-year population-based machine-learning study

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Aim:** Existing dementia risk prediction models, although numerous, have predominately been developed from Western populations. By combining theory-driven and data-driven methods, this study aimed to develop a clinical algorithm that utilizes machine learning to predict dementia diagnosis in Chinese older adults and by age groups, guided by the cognitive footprint theory.

**Method:** Population-based electronic medical records from the Clinical Data Analysis and Reporting System in Hong Kong were employed. We included all patients with dementia diagnosed at 65+ between 2010 and 2018, and controls without dementia that were 1:1 matched by age, sex, and index date. A total of 51 features, comprising exposures to established and exploratory risk factors before and after the age of 65 years, were identified from records spanning from January 1, 2000, to the first diagnosis of dementia. The prediction accuracies of seven machine learning models, including LASSO, Random Forest, Multilayer perceptron (MLP), gradient boosting, XGBoost, LightGBM and categorical Naïve Bayes, were compared with logistic regression model for dementia risk overall and by age groups.

**Results:** A total of 159,920 individuals (40.5% male; mean age [SD]: 83.97 [7.38]) with and without dementia were included. Compared with the logistic models, machine learning models showed better performance, particularly the gradient boosting algorithms and MLP model. Exploratory risk factors such as antipsychotic medications, antidepressants, vascular diseases, polypharmacy, nutrition and dyslipidemia were identified as important predictors. Age-specific models differed, where neurological or psychological diseases and medication use were more important in younger age groups, and cardiovascular diseases and infectious disease became prominent in older age groups.

**Conclusion:** Our machine learning based prediction model showed satisfactory predictive power in identifying patients with an increased likelihood of dementia. The algorithm can be used in clinical practice to allow precise and timely primary interventions in a cost-effective manner.

#### **Keywords**

dementia, cognitive footprints, machine learning, electronic medical records



## Language reversion among migrants living with dementia in community settings: Impact and Implications.

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#### **Topic**

Dementia diagnosis, treatment, care and support: Migration, care and dementia

#### **Abstract**

**Aims:** Culturally and linguistically diverse (CALD) migrants living with dementia often experience language reversion, social isolation, and limited support. Such care challenges remain understudied. The aims of this two-phase study are to synthesise research evidence on challenges and opportunities in the care of CALD migrants with dementia and language reversion (Phase 1), and to understand the care needs and the approaches to meet these needs for CALD migrants living with dementia and language reversion in an Australian social context (Phase 2).

**Method:** In Phase 1, a systematic review is undertaken to search and synthesise research evidence on language reversion and its impact on the care of CALD migrants with dementia in a global context. In Phase 2, an interpretive phenomenological analysis is applied to understand the care needs and care services that meet the care needs based on the experiences of CALD migrants and their care partners (informal and professional carers). In-depth interviews and focus groups will be used to collect data from participants and thematic analysis will be applied to analyse data and present findings.

**Results:** The systematic review is ongoing and preliminary findings indicate the lack of timely recognition, accurate assessment, targeted interventions for CALD migrants with dementia experiencing language reversion in the community care settings. The opportunities to address these care challenges include, but are not limited to, promoting person-centred care, empowerment, and social engagement, and providing culturally and linguistically congruent aged care services for this population. Findings from Phase 2 of the project will enhance the understandings of the care needs and care practice to meet these needs for this population in an Australian socio-cultural context.

**Conclusions:** Findings from this two-phase study will underscore the need for equitable dementia care for CALD migrants living with dementia and experiencing language reversion.

#### **Keywords**

assessment, care needs, community-dwelling, cross-cultural, culturally and linguistically diverse, culturally appropriate care, language reversion, migrants, person centred approach, social support



## The 'Flemish working group of people with dementia': our call to action for respectful communication

Mr Olivier Constant, Mr Paul Goossens, Mrs Katelijne Lefevere

Alzheimer Liga Vlaanderen (Flemish Alzheimer's Association), Turnhout, Belgium

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Words can make or break. That is why the 'Flemish working group of people with dementia' launched an innovative awareness raising campaign in 2023 on respectful communication as the foundation for an inclusive society. In eight video statements the members of the working group offer a clear call to action for language use that does justice to the daily reality of people with dementia. In addition, they wrote a media manifesto together to make the written and audiovisual press aware of the impact of language and images on the quality of life of people with dementia. Following the manifesto, they developed little boxes with cards as a playful action to ban disrespectful words and highlight respectful alternatives.

Focusing on the lived experience of people with dementia makes you look at the condition differently. And if you also give people with dementia a central place in your reporting on the theme, words and images become more realistic, more respectful and more credible. A win-win for everyone! In this presentation, the campaign is presented by the working group itself on the basis of a personal testimony and more information about the campaign tools. To conclude, we look back at the impact of the campaign and the intensive but fascinating road we traveled together during the co-creation process.

#### **Keywords**

awareness raising, sitgma, inclusion, respectful communication, experts by experience, Flemish working group of people with dementia



## "Empowering Voices: Public Patient Involvement, Personhood, Citizenship, and Agency in Dementia Advocacy"

Ms Carmel Doris Geoghegan, Ms Helen Rochford Brennan

Dementia Ireland Empowering Communities, Connemara, Ireland

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

In a world where the capabilities of individuals living with dementia and their caregivers/supporters are often underestimated or overlooked, the concept of Public Patient Involvement (PPI) emerges as a powerful force for change, emphasizing personhood, citizenship, and agency. This abstract introduces the compelling narrative of how PPI can transform the landscape of dementia advocacy, reinvigorating the forgotten principles of personhood, citizenship, and agency. PPI extends beyond mere participation; it signifies the empowerment of those living with dementia and their caregivers/supporters, acknowledging their personhood, their rights as citizens, and their agency in shaping their own narratives.

The presentation will highlight the essential elements of PPI, emphasizing the need for inclusivity and accessibility. It will stress the importance of accommodating the unique requirements of both individuals, including travel support and transparent communication with organizers to ensure their active participation as engaged citizens.

It will delve into the invaluable experiential knowledge that individuals with dementia and caregivers/ supporters bring to the table, reinforcing their agency in contributing to research and policy discussions. Their firsthand experiences can revolutionize research, contributing to more patient-centred and impactful outcomes.

This presentation will also acknowledge the limitations of PPI, emphasizing the need for a balanced approach that prioritizes both involvement and the well-being of participants while safeguarding their personhood and agency. Beyond research, PPI plays a pivotal role in shaping policy, raising awareness, and reducing stigma, highlighting the transformative impact of including individuals with dementia caregivers/supporters as active citizens in advocacy efforts, thereby fostering a compassionate and inclusive society.

In summary, the abstract introduces a compelling narrative of empowerment, inclusivity, and transformation in the realm of dementia advocacy. It invites conference attendees to explore the profound impact of including the voice of the lived experience.

#### **Keywords**

Public Patient Involvement, Advocacy, Personwithdementia, Supporter, Carer, Research, Personhood, Livedexperience, Empowerment, Inclusivity, Dementia, Communication,



#### Exploring public perception of dementia on Twitter (X): a crosscultural analysis

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#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Background:** The World Health Organization launched the Global Action Plan for the Public Health Response to Dementia in 2017 to promote dementia-friendly environment. Since then, limited studies have assessed social perceptions of dementia using digital media.

**Aims:** To analyze and compare public perceptions of "dementia" in English and Thai Tweets and explore chronological change of the perceptions between 2017-2021.

**Method:** Tweets containing "dementia" or "#dementia" and their Thai equivalents from May 2017 to April 2021 were collected via the Twitter Application Programming Interface. Thai tweets were collected comprehensively, while English tweets were randomly selected for each period. Irrelevant- and re-tweets were removed. We identified tweet owners, classified sentiment (positive, neutral, or negative), and determined specific topics. Three investigators (internist SS, geriatrician TC, linguist PP) simultaneously analyzed 5% of tweets in both languages for consistency and reliability. The internist completed the remaining analysis.

**Results:** 9,511 Thai and 10,062 English dementia-related tweets were analyzed. General users were the most prevalent in Thai (8692 tweets, 91.4%) and English (6642 tweets, 66.0%). For sentiment analysis, 81.3% of Thai tweets were negative, compared to 44.2% of English tweets. However, only 3% of tweets in both languages had positive sentiment. "Dementia" was commonly used correctly in English tweets (39%) but often misused in Thai tweets (49.2%). Both languages exhibited high usage of "dementia" as a stigma: 78.2% in Thai and 41.4% in English. Thai tweets showed stigma levels from 73.6% to 83.3%, with the highest rate in 2020, while English tweets ranged from 24.6% to 64.4%, also peaking in 2020.

**Conclusion:** Substantial numbers of English and Thai tweets held negative perceptions of "dementia," and it was frequently used for stigmatization on Twitter(X). Creating a dementia-friendly community requires action at all levels of dementia care to raise awareness and prevent inappropriate use of the term.

#### **Keywords**

dementia, stigma, twitter, X, Thai, English



## Involving implicit measurements in future dementia research: children's drawings for the identification and modification of negative stereotyping of Alzheimer's Disease

#### **Dr Kasper Bormans**

Maastricht University, Maastricht, Netherlands

#### **Topic**

**Dementia awareness:** Attitudes, awareness and stigma

#### **Abstract**

**Aims.** Most countries in Western civilization are segregated societies with little or no contact between generations. Elementary schools and nursing homes are separated worlds in proximity. Children alienate further from the elderly and rely on indirect experiences with old age and dementia. The elderly can embody negative stereotypes from media and society leading to disparities in health care, social isolation and loss of functional ability.

**Method.** In this study we collected 796 drawings from 98 children in 6 elementary schools in Belgium and The Netherlands. The 10-y-old pupils made portraits of grandparents and the elderly in neutral, happy and unhappy conditions. The standardized drawing assignments were repeated after a psychosocial intervention program of 16 weeks to connect generations. The effects of non-pharmacological interventions in Alzheimer's research are mostly studied with classical questionnaires. These tools are insufficient to detect implicit motives and subtle mental representations of old age and dementia. Before and after drawings are an added value to the field of research. The implicit measurements circumvent social desirability, go beyond the level of awareness and give a clearer picture of negative stereotypes of old age and dementia.

Results. The content analysis of the drawings demonstrated that children represent 'happy elderly people' as: outdoors, active, and surrounded by others, while 'unhappy elderly people' are generally portrayed indoors, sedentary and lonely.

**Conclusion.** Children's drawings as implicit measurement are an added value for psychosocial interventions. The act of drawing is pleasant, easy and effective for the identification and modification of negative stereotyping of old age and dementia.

#### **Keywords**

implicit measurements, children's drawings, breaking stigma, intergenerational research



## CURATE-D Erasmus + Project: : Inclusion in the cultural sector for people living with dementia

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#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

In recent times, there has been a noticeable shift within Arts and Culture organizations towards creating more inclusive cultural experiences. Studies, such as the scoping review conducted by Delfa-Lobato et al, emphasize the benefits of such activities/interventions for individuals living with dementia (pwD). In line with this trend, Erasmus + project "CURATE-D: A Game-based methodology for empowering Dementia friendly communities and equal access to Culture for people with Dementia" (Project Code: 2022-1-EL01-KA220-VET-000085409) aims to empower professionals in the cultural and caregiving sectors to support pwD in cultural activities.

The key objectives include

- promoting social inclusion and equal cultural accessibility for pwD,
- adapting Vocational Education and Training (VET) programs to meet contemporary accessibility needs, and,
- developing an innovative educational methodology and toolkit for VET education.
- Its results comprise a methodological guide tailored to the project, offering a comprehensive
  framework for professionals, two training guides for cultural venue staff and professional caregivers,
  including game-based lesson plans and a serious game acting as an engaging and interactive
  learning resource. Additionally, during the project's lifetime, the partners will organize and implement
  professional training programs and provide a Conclusions report encapsulating its findings and
  recommendations for future use
- The project will last 24 months and is coordinated by CHALLEDU (Greece) and the partnership
  includes the Panhellenic Federation of Alzheimer's Disease and Related Disorders (Greece), The
  Gaiety School of Acting The National Theatre School of Ireland (Ireland), ASOCIACIÓN FAMILIARES
  ALZHEIMER VALENCIA (Spain) and HERAKLEIDON MUSEUM (Greece).

The aim of this presentation is to disseminate the project's methodology and results.

#### **Keywords**

inclusion, Vocational Training, arts and culture, dementia friendliness, museum activities, game based learning



## The prognosis of mild cognitive impairment: a systematic review and meta-analysis

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#### **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Rationale:** knowledge gaps and controversies persist on the prognosis of MCI: highly variable conversion rates have been described and reversion to normal cognition has only recently been thoroughly analyzed. In light of the exponential growth of prognostic studies focusing on MCI, we aim to update the evidence on the risk of conversion to dementia integrating it with the recent data on reversion and stability rates. To our knowledge, this is the first systematic review that comprehensively evaluates the different cognitive trajectories of MCI.

**Materials and Methods:** All available studies published up to June 2023 were retrieved by searching the PubMed, APA PsycInfo, and CINAHL databases. We included observational/experimental, retrospective/prospective, clinical/population setting studies evaluating the prognosis of MCI, with at least a 3-year follow-up. MCI and dementia diagnoses should align with established international criteria.

**Results:** we included 91 studies evaluating a total of 33.198 participants. Conversion and reversion rates were 43% (95%CI: 39%-46%) and 12% (95%CI: 7%-16%) in clinical-based studies and 28% (95%CI: 22%-35%) and 28% (95%CI: 17%-39%) in population-based studies. AD dementia was the most frequent diagnosis (overall mean frequency: 72.0%) followed by VaD, with similar mean frequencies between settings. FTD and DLB diagnoses showed higher mean frequencies in the clinical-based compared with the population-based setting (7.0% vs 4.9% and 6.1% vs 3.4%, respectively).

**Conclusion:** Within the limits of high heterogeneity, we observed a greater likelihood of conversion in the clinical-based setting and a probability of reverting to normal cognition three times higher in the population-based setting. Up to 50% of patients with MCI did not convert to dementia even in the studies with the longest follow-up (≥5 years) and annual conversion rates decreased with longer follow-ups. Our data might be helpful to improve clinical practice and support the organization of sustainable dedicated care pathways.

#### **Keywords**

MCI, prognosis, dementia, conversion, reversion



## iSupport for Young People as a tool to explore the needs of Brazilian and Spanish youngsters who live in a family affected by dementia

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<sup>1</sup>Bangor University, Bangor, United Kingdom. <sup>2</sup>Universidad de Salamanca, Salamanca, Spain.

#### **Topic**

Support for dementia carers: Young carers

#### **Abstract**

#### Background: aims and work underway

Evidence shows that across the world young people affected by parental or grandparental dementia are under supported. In response to this, iSupport for Young People was developed; the first online tool of its kind, providing training and support to this group so they can understand dementia, how it can affect their family member and what changes are expected. It consists of 22 lessons distributed across five modules: Introduction to dementia; Being a carer; Caring for me; Providing everyday care and Dealing with behaviour changes. The lessons comprise relevant information, caregiving scenarios and interactive skills training exercises. The aim of this study, which started in September 2023 and will run for 12 months, is to extend the reach and significance of iSupport for Young People through working with international partners and relevant stakeholders in Spain and Brazil. Specific objectives are:

- To professionally translate iSupport for Young People to Spanish and Brazilian Portuguese
- To organize a series of showcase events in each country to provide a platform for discussions on how to increase the awareness and support available to this vulnerable group.
- To explore the contextual factors that will play a role in adapting iSupport for Young People so it can be embedded within current service pathways in Spain and Brazil

By bringing a spotlight onto young people living in Brazilian and Spanish families affected by dementia we hope to start the conversation and build the foundations of evidence-based research to increase identification, awareness and 'fit for purpose' support initiatives across Spain and Brazil.

#### **Keywords**

Young person, Young carer, Adolescents, Younger Onset Dementia, Dementia, Carer, Schools

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## iSupport: Pilot randomised-controlled trial of iSupport New Zealand adaptation

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Aims:** This study is part of Empowering Dementia Carers with an iSupport Virtual Assistant (e-DIVA), a cross-country collaboration between Australia, Indonesia, New Zealand (NZ), and Vietnam to locally adapt the iSupport for Dementia programme. In 2022-2023, we co-designed iSupport-NZ adaptation with local carers and developed it into an online course hosted by the cross-country e-DIVA website. We aim to assess the usability, acceptability, and preliminary impacts of this website on carers' stress and quality of life through a pilot randomised-controlled trial (RCT).

**Methods:** This two-arms waitlist pilot RCT recruited 40 carers (20 Māori, 20 non-Māori). Inclusion criteria: 1) adult primary unpaid carers of persons with dementia residing in NZ, 2) had been providing care at least six months, 3) had access to a gadget with an internet connection, 4) Perceived Stress Scale (PSS) > 13. Participants were stratified based on ethnicity and randomised equally into Group 1 (Intervention, n=20, received e-DIVA website access immediately) or Group 2 (Waitlist control, n=20, received access three months after). Both groups were expected to use the website for at least three months. Primary outcome measures: carers' Perceived Stress Scale and Visual Analog Scale of Quality of Life, assessed at baseline, 3- and 6-months. Exit interviews were done at 6 months to gather qualitative feedback.

**Results:** Preliminary results will be presented at this conference.

**Conclusions:** The results of this study will inform the need for further refinement of e-DIVA website and the feasibility of doing a larger trial.

#### **Keywords**

iSupport, nonpharmacological approach, support for carers, dementia education, online support



### iSupport - The effectiveness of a Chinese iSupport for Dementia program for family carers in Australia and Greater China

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aims:** The aim of the study was to determine the effectiveness of a culturally adapted Chinese iSupport program for carers of people with dementia (PLWD) in the Chinese-Australian community and greater China.

**Method:** The study applied a multicentre randomised controlled trial. Participants were recruited from community settings. Carers in the intervention group were engaged in skill training using the iSupport, participated in a facilitator-led monthly group meetings, received needs-based support from the facilitator and interactions with peers using WhatsApp or WeChat. The intervention lasted 6 months and all participants were followed up for an additional 3 months after completion. Carers in the usual care group received support provided by the Alzheimer's Association and received the iSupport after the study. Outcome measures were carers' quality of life (QoL), self-efficacy and social support, changed behaviours in PLWD, carers' reactions to the behaviours, the QoL of PLWD, unplanned hospital admissions and emergency department presentations by PLWD. Intervention effectiveness was determined using a multivariate mixed effect linear regression model.

**Results:** Of the 266 carers recruited, 171 completed the trial. Carers in the intervention groups showed significantly improved mental health-related QoL (+3.74 adjusted mean scores, 95% CI 2.98-4.74, p=0.001 at 6 months), self-efficacy in controlling upsetting thoughts and reduced reactions to changed behaviours of PLWD, compared to the usual care group. PLWD cared for by carers in the intervention group also had fewer admissions to hospital and emergency department presentations compared to those in the usual care group, but the differences were not statistically significant. Other outcome measured showed no statistically significant differences between groups. Qualitative data from the intervention groups indicated increased peer support and reduced social isolation.

**Conclusions:** The Chinese iSupport program can improve carers' mental health, peer support and social connections, reduce upsetting thoughts and reactions to changed behaviours of PLWD.

#### **Keywords**

community aged care; dementia; family caregivers; nursing; online education; quality of life; RCT; self-efficacy; virtual social support



#### iSupport - Adaptation of iSupport for different populations

Prof Aimee Spector<sup>1</sup>, **Ms Emily Fisher**<sup>1</sup>, Ms Bethan Naunton Morgan<sup>2</sup>, Prof Annette Hand<sup>3</sup>, Dr Kate Greenwell<sup>4</sup>, Dr Andrew McCarthy<sup>3</sup>, Ms Joy Milne<sup>5</sup>, Ms Banika Ahuja<sup>1</sup>, Ms Suman Kurana<sup>1</sup>, Ms Aziza Begum<sup>1</sup>, Dr Patricia Masterson-Algar<sup>2</sup>, Mr Greg Flynn<sup>2</sup>, Prof Gill Windle<sup>2</sup>, Prof Joshua Stott<sup>1</sup>, Dr Carolien Lamers<sup>2</sup>, Mrs Joanna Slodkowska-Barabasz<sup>4</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** There is a pressing need for interventions tailored to diverse clinical and demographic populations of dementia caregivers. Many online interventions do not address the specific care needs of people living with rare dementia or Parkinson's disease with cognitive impairment. South Asian carers in the UK are also underserved in research, and high levels of stigma and pressures to keep care within the family can limit help-seeking. The World Health Organization's 'iSupport' is an online intervention that can be tailored to meet the needs of diverse populations.

**Method:** 'iSupport' has been adapted for caregivers of 1) people with posterior cortical atrophy, primary progressive aphasia, frontotemporal dementia, and Lewy body dementia, 2) people with Parkinson's disease and cognitive impairment ('iSupport-PD'), and 3) UK-based South Asian people with dementia. We have carried out stakeholder consultation and co-design with caregivers, healthcare professionals, and charity representatives, including focus groups and semi-structured interviews.

**Results:** We will present the main components of the adapted online interventions Adaptations of 'iSupport' for rare dementias include prioritising content on behavioural and visual rather than memoryled symptoms; new content reflecting the younger age of onset; and making advice less prescriptive, instead encouraging a person-centred approach. Adaptations for the UK South Asian population include tailoring translations and cultural nuances that reflect the South Asian diaspora; using audio to increase access to carers with a range of literacy levels; and addressing misconceptions about defining oneself as a caregiver. We will also discuss feasibility and acceptability and report initial results from a randomised controlled trial of 'iSupport-PD'.

**Conclusion:** These tailored interventions will better support the knowledge and skills of varied caregiver populations. The e-health approach enables broad reach and reduces geographical boundaries, providing access to those living in areas where condition-specific or culturally tailored local services are not available.

#### **Keywords**

caregivers, e-health, equity, stigma, awareness, training, education



### iSupport - Applying the eHealth Literacy lens to evaluate a virtual assistant to support family carers of people with dementia

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#### **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Introduction:** We have co-produced with carers of people with dementia (hereafter carers) a culturally tailored iSupport Virtual Assistant (VA), namely e-DiVA, to support English-, Bahasa- and Vietnamese-speaking carers in Australia. The presented research reports qualitative findings from the e-DiVA user-testing study.

**Methods:** Family carers and healthcare professionals working in the field of dementia care were given access to e-DiVA to use on their smartphone/handheld device for 1-2 weeks. They tested all functions and content of the VA and provided feedback in a 'Think-aloud' session, either in person or online. Data was analysed thematically, guided by the eHealth Literacy Framework (eHLF).

**Results:** Eighteen family carers and nine staff of aged care providers were recruited. Participants discussed all seven domains of eHLF, which were evidenced in e-DiVA. They include: 1) ability to process information, i.e. the VA contains information in a format that can easily be understood, e.g. animations; 2) engagement in own health, i.e. providing tailored lessons through need assessments and 'chatbot'; 3) ability to engage actively with digital services, i.e. providing user manuals; 4) feeling safe and in control; i.e. secure login; 5) motivation to engage with digital services, i.e. providing quick responses/solutions to carers' queries; 6) having access to systems that work, i.e. ability to access to the VA anytime anywhere; and 7) digital services that suit individual needs, i.e. available in users' preferred language. Participants highly ranked domains 1, 2 and 5. They suggested further improvements including making content into audiobooks and messages (domain 1). Participants also indicated potential barriers to use, especially within domains that require interactions between individuals and the digital system (domains 3, 5 and 7).

**Conclusion:** Findings show the high acceptance of the VA by both the carers and aged care providers, as well as a need for enhancement to improve accessibility.

#### **Keywords**

carers, dementia, e-DiVA, eHealth Literacy, iSupport, virtual assistant



### iSupport: A Randomized Controlled Study of an Internet-Based Self-Education System for Caregivers in Japan

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** Providing care for individuals with dementia brings significant financial, physical, and emotional challenges. In Japan, family caregivers often struggle due to insufficient time and resources for understanding dementia management and self-care. The World Health Organization (WHO) has introduced iSupport, an online program offering self-education, skill training, and cognitive-behavioral therapy-based support for caregivers. We adapted and developed the Japanese version, iSupport-J, and initiated a randomized controlled study (RCT) to assess its efficacy.

**Methods:** This RCT, decentralized for caregivers, recruited participants through advertising and word-of-mouth referrals. Remote consent and assessments were conducted via mailed documents, emails, and an electronic patient-reported outcome (ePRO) system. Caregivers experiencing distress (measured by Zarit Burden Interview scores exceeding 21 points) and depression (more than 4 points on the Center for Epidemiological Studies Depression scale) were randomly assigned to the 3-month iSupport-J program or placed on a waitlist. iSupport-J comprises five modules: "Introduction to Dementia," "Being a Caregiver," "Caring for Me," "Providing Everyday Care," and "Dealing with Challenging Behaviors." Participants in the iSupport-J group had unrestricted access to all modules via their smartphones or computers. The primary outcome measured was the change in ZBI scores from baseline at Month 3.

**Results:** From January 2021 to May 2023, a total of 248 participants enrolled in the study (127 in the intervention group and 119 in the waitlist group). One participant withdrew from the intervention group, and 18 failed to report Month 3 evaluations within the specified timeline. In contrast, no withdrawals occurred in the waitlist group, with five participants failing to report.

**Conclusion:** We successfully recruited participants and anticipate sharing results at an upcoming conference. Our findings will underscore the significance of remote interventions for caregivers with limited access to learning and self-care resources.

#### **Keywords**

Caregiver burden, Self-education, Cognitive Behavioral Therapy, Internet-based intervention, Behavioral and Psychiatric Symptoms



### iSupport - The cultural adaptation of iSupport program: Experiences from Australia, Brazil, Indonesia, New Zealand, and Qatar

**Prof Tuan Anh Nguyen**<sup>1,2,3</sup>, Ms Danielle McCalmont<sup>4</sup>, Ms Leona Kosowicz<sup>4</sup>, Ms Tara Sani<sup>5</sup>, Dr Sarah Cullum<sup>5</sup>, Prof Yuda Turana<sup>6</sup>, Dr Déborah Oliveira<sup>7,8,9</sup>, Dr Mani Chandran<sup>10</sup>, Prof Bianca Brijnath<sup>4</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** To support dementia carers, the World Health Organization (WHO) developed iSupport program, culturally adaptable to local contexts. This study aimed to draw lessons about iSupport adaptation in Australia, Brazil, Indonesia, New Zealand, and Qatar.

**Methods:** A questionnaire regarding modifications of the WHO iSupport adaptation methodology, changes to the WHO iSupport manual, and the enablers of and barriers to the iSupport adaptation was sent to the iSupport adaptation teams in the five countries. Data were analysed thematically.

**Result:** Countries modified the WHO adaptation methodology, undertaking more focus group discussions (FGDs) than recommended. iSupport manual was divided into smaller, more manageable sections. Individual participants only reviewed a section to reduce burden.

Common adaptation includes changes to language to be more empathetic. Australia and New Zealand added modules about person-centred care principles and access to formal care services. Brazil added topics such as fall prevention.

Four countries identified short video clips as a method to increase usability and accessibility to iSupport. In Australia, scenarios from iSupport were translated into scripts then storyboards and 51 animations were produced via an iterative, ongoing stakeholder feedback process. Themes emerged include an emphasis on carers understanding of the disease, validating their experiences and emotions and creating authentic content that genuinely reflects caring for someone with dementia. New Zealand and Indonesia adjusted Australian animations to suit their local contexts through modifications to terminology and animation characters. Qatar developed five short videos, each reflecting a module of the iSupport, to encourage carers to seek further information in the adapted iSupport program.

**Conclusion:** Modifications of the current WHO iSupport Adaptation and Implementation Guidelines are needed. There is a need to improve the accessibility and usability of the iSupport online program, with the inclusion of short video clips being one possible solution.

#### **Keywords**

iSupport, Dementia, Carer, cultural adaptation, culture,



#### Implementation of Global Action Plan On the Public Health Response to Dementia (GAPD) in Sub-Saharan Africa: Comprehensive Reviews

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

**Background:** Despite the fact that, age is a strongest know risk factor for onset of dementia, and developing countries are projected to have highest number of ageing population, few national dementia strategies have been put in place to address this impending scourge. In 2017, World Health Organization(WHO) released and called for countries to adapt and contextualize the Global Action Plan on the Public health response to dementia, few Sub-Saharan countries have slowly adopted plan. The outcome of the unprecedented increase populations with dementia will be immense.

**Methods:** This paper is a view of published and grey literature relevant to Global Action Plan On the Public Health Response to Dementia (GAPD) in sub-Saharan Africa. The overall approach to the review had an exploratory and inductive focus. Articles were categorized around a guiding conceptual framework. Like; A description of structural arrangements and content of national dementia strategy development and normative underpinnings within policy frameworks

**Results:** Nearly all countries within the SSA hadn't developed the national dementia strategy plans. Countries like South African, Ghana, Kenya and Ethiopia had drafts of national dementia strategy, though not yet operationalized. Few countries highlighted some of the parallel targets of GAPD within their national mental health policy and strategy, but it was not comprehensive. Countries where Civil societies that advocate/champion dementia activities were strongly presently were more likely to possess a draft of GAPD.

**Conclusion:** Although there some initiatives for different countries to develop national strategy for dementia plans, there are gaps in the extent of engagement of different stakeholders and how these strategies will be operationalized may limit the impact on addressing the escalating burden of dementia in Sub-Saharan Africa.

#### **Keywords**

Dementia, Sub-Sarahan Africa, national plans, GAPD



### The Role of Egyptian Alzheimer Association in Raising Awareness about Alzheimer's Dementia

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

The Egyptian Alzheimer's society was founded by the late professor Abd El Moneim Ashour in 1999. It is a member of Alzheimer's Disease International (ADI).

The main concern is to raise awareness about the early signs of Dementia and the importance of early diagnosis and knowledge of risk factors along with the risk reduction of them, in addition to support for care providers, emphasizing the importance of social engagement and behavioral interventions, especially with the limited role of medication till now.

Its activities are conducted in collaboration with the Neuropsychiatric departments and the geriatric departments in different universities in EGYPT, also there is an agreement with the Ministry of Health to provide training courses for the health care providers including psychiatrists , nurses , psychologists and social workers to deal with the patients and their relatives . Awareness campaigns was done on monthly basis in the form of 'Alzheimer Café ' along with the celebration of World Alzheimer's Day in September every year .

Person living with cognitive impairment, their family members, and their care providers have all identified "quality of life" as a central goal in the treatment of dementia and the society has a role in helping them in their journey through its activities.

Many workshops were done to highlight the non-pharmacological interventions with people living with dementia aiming to improve well-being and independence also teach the family members how to provide a safety environment for the Alzheimer patients. Many awareness campaigns trough the media and social media , also in collaboration with the Egyptian Coptic church and El Azhar .

Dignity in old age and the provision of care and assistance to older people is a value that requires guaranteeing the right to free choice and participation in decision-making.

#### **Keywords**

Risk Reduction, Alzheimer, Dementia, Awareness



### Identifying Dementia Care Partner Supports as a Public Health Priority: Addressing Unmet Population Health Needs

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#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### Abstract

**Aims:** To determine supports needed by care partners (CPs) of people living with dementia (PLWD), by empowering population groups historically/currently underserved in dementia research and services, and recommend public health policies and interventions to improve CP wellbeing through social supports and programs.

**Method:** Caregiving-related priorities of CPs for PLWD (focused on 4 historically underserved communities) were determined using 5 focus groups and 24 in-depth interviews conducted over 6 months with CPs and organizations providing services that support PLWD in Oregon. Key governmental and nonprofit organizational leaders participated in a modified Delphi process to identify social priorities for supporting CPs through policies and programs.

**Results:** Unmet needs affect the ability of CPs to manage caregiving and vary across populations, due to cultural traditions, systemic inequities, and structural racism. CP needs were grouped into 8 themes related to support mechanisms, programs/services, information resources, care coordination, technology, financing, workforce development, and policy. CPs were generally satisfied with clinical dementia care yet identified opportunities for new or enhanced social supports.

**Conclusions:** Supporting CPs of PLWD could reduce health impacts of caregiving, improve personal well-being, and reduce or delay institutional living for PLWD. To ensure equitable supports across diverse populations and alignment with the Global Action Plan on the Public Health Response to Dementia 2017-2025, policymakers at all levels of government must engage with CPs from underserved communities to enhance access to the breadth of culturally appropriate services, and CPs' needs for supports that address social determinants of health must be central to these policies.

#### **Keywords**

dementia, care partners, public health, policy



### Determining the top research priority topics for Lewy body dementia in Ireland taking a multi-stakeholder approach

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#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

**Aim:** Lewy body dementias (LBD) remain significantly under-represented in dementia research, and people with lived experience rarely have the opportunity to set the research agenda. We aimed to address this gap by conducting a multi-stakeholder Priority Setting Partnership (PSP) in the Lewy body space.

**Methods:** We conducted an Irish national collaborative study that took a 3-stage approach: Stage 1) Al topic modelling of the global LBD literature to identify the most frequently researched topics about LBD; Stage 2) A scoping review of LBD research priorities to generate a 'long list' of research priority questions (RPQs); Stage 3) An online survey to identify the ten most important RPQs for LBD in Ireland. Participants included adults living with LBD, family carers, and healthcare professionals in relevant specialities who have managed or experienced LBD.

**Results:** Al modelling yielded 522 abstracts, highlighting the leading research areas in LBD globally, including diagnostic classification, prevalence, clinical data, and biomarker features. A prioritisation survey was undertaken, garnering responses from 46 individuals. Of these respondents, 70% were researchers or healthcare professionals, while 30% were individuals with lived experience. This survey distilled the research focus into ten key RPQs, ranging from LBD's causes and risk factors to its progression, diagnostic challenges, support services, and treatments.

**Conclusions:** The RPQs highlighted evidence gaps in LBD research, encompassing both clinical aspects and the lived experiences of those directly impacted. These findings will steer future research pertinent to the Irish population and beyond, providing valuable insights for researchers and funding bodies.

#### **Keywords**

Lewy body dementia, Priority Setting Partnership, Al modelling, Research Priority, Scoping Review, Stakeholder Engagement



### Promote DemenTitude® - 16 Principles of Proper Caring Attitude from the Voice of People with Dementia in Hong Kong

#### **Dr CHI MAN KENNY CHUI**

Hong Kong Social Worker Assoication, Hong Kong, Hong Kong

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Caring is not just only focusing on knowledge and skills but also the "attitude". In preserving personhood through the person-centred care approach, synchronising with the experience of the person with dementia and listening to his/her voice of interpreting the surrounding things should be promoted. Qualitative research with in-depth interviews and participatory observations was conducted in the community care and residential care homes of Hong Kong. Following the theoretical framework blending interpretivism and the sociocultural perspective on dementia in Hong Kong, the 16 principles of proper caring attitude, called DemenTitude®, were formulated from the findings.

The 16 principles were translated from Cantonese to English (1) Unveiling limitless interpretations; (2) Listening more than criticise; (3)Memories fade, history endures; (4) Communication is all about interaction; (5) Trusting their feeling and perception; (6) The same stays the same; (7) Behavior speaks; (8) Beyond the matter-of-fact; (9) Process is the key for assessment; (10) Dignity through equality, treat as adults; (11) Meaningful engagements form life; (12) Mind your words; (13) The power of touch is better than words; (14) Person-centred Care always as the root; (15) Quality and Quantity, both counts; (16) Care takes priority, "attitude" over "speed". An educational package was designed with these 16 principles regarding the local context and cultural adaption. The aims are to reduce the stigma of dementia among the caring staff and to raise awareness of dementia-inclusive language. The evaluation of this educational training showed a significant improvement in the positive perception of dementia among the participants.

#### **Keywords**

DemenTitude®, Attitude, Qualitative research, Voice of people with dementia, Hong Kong, Dementia care education



### Embedding the voice of lived experience within policy and practice in Scotland

Miss Alice Motion, Ms Maxine Meighan, Dr Kainde Manji, **Miss Dina Roggero** About Dementia, Age Scotland, Edinburgh, United Kingdom

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

Scotland has been world-leading in its approach to dementia in policy and practice, naming dementia a public health priority in 2007 and the creation of four national dementia strategies to date Scotland also leads by example with dementia friendly communities, which have grown in number over the last decade.

The most recent strategy; 'Dementia in Scotland: Everyone's Story' was published in June 2023. This strategy offers a 10 year vision, focusing on empowering and hearing the voice of lived experience. A 'National Conversation' between October to December 2022 was held to inform the new strategy

As Scotland's Policy and Practice forum, About Dementia works directly with voices of lived experience to influence change in dementia policy and to ensure these voices are embedded into policy.

We adopted a storytelling methodology as part of our engagement in the 'National Conversation.' This approach requested that attendees give tailored advice to a fictional character experiencing dementia. . This 'one step removed' approach situated the person with dementia as the 'expert' created a cathartic environment for people to talk about dementia and enabled a safe space to hold important conversations including:

- Finance
- Self-Directed Support
- Community Support
- Care and Complaints
- Human Rights
- Primary Care

The majority of sessions took place in-person, and in communities that people living with dementia were already a part of, reaching approximately 267 people living with dementia (N=83), unpaid carers (N=84), and professionals (N=100).

Our work towards the new National Dementia Strategy enabled often forgotten or inaccessible voices to be heard. It taught us that each person affected by dementia has a different perspective and a different experience. Our work highlights the importance of not overlooking people directly affected by dementia as key players in the development of policy and practice.

#### **Keywords**

lived experience, community based support, dementia friendly community, post diagnostic support, dementia strategy, human rights, storytelling,



## Maintain Your Brain - outcomes and implications of a 3-year randomised controlled trial of personalised online intervention to prevent cognitive decline

**Prof Henry Brodaty**<sup>1</sup>, Dr Megan Heffernan<sup>2</sup>, Ms Tiffany Chau<sup>3</sup>, Prof Maria Fiatarone Singh<sup>4</sup>, Prof Michael Valenzuela<sup>3</sup>, Prof Perminder S Sachdev<sup>3</sup>, Dr Michael Millard<sup>5</sup>, Prof J. Anupama Ginige<sup>6</sup>, Prof Kaarin Anstey<sup>7</sup>, Prof Nicola Lautenschlager<sup>8</sup>, Prof Louisa Jorm<sup>9</sup>, Prof John McNeil<sup>10</sup>, Dr Nancy Briggs<sup>11</sup>, Dr Gordana Popovic<sup>11</sup>

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** Preventing cognitive decline in person has had mixed results. Online approaches are more scalable and feasible to deliver at a population level, no multimodal online intervention has yet demonstrated efficacy. We aimed to reduce cognitive decline with ageing using an online package of interventions delivered intensively for 12 months followed by monthly boosters for 24 months.

**Methods:** Invitations were sent to people aged 55-77 years from the 45 and Up study, a population-based cohort study of one-in-ten people aged 45 years and older in NSW, Australia (n=267,000). Participants were required to be eligible for >=2 of 4 modules addressing Physical Activity, Nutrition, Cognitive Activity and mental well-being. Participants received modules based on their risks, with 1:1 randomized allocation to active personalised coaching modules (intervention) or static information-based modules (control). The primary outcome was change in an online combined multi-domain cognitive score. Secondary outcomes included specific cognitive domains and dementia risk scores.

**Results:** Of 96,418 invitations issued, 14,064 (14%) consented, 11,026 (11%) were eligible and 6,104 (6%) completed all baseline assessments. Over three years, using intention-to-treat analysis, the intervention group improved significantly more in the global composite cognition z-score ES=0.18 (p<0.001). Significant benefits were found for complex attention, executive function and learning and memory (all p<0.001), and dementia risk (p=0.007).

**Conclusion:** An online platform tailored to individuals' risk factor profiles over three years significantly delayed cognitive decline in older adults. This platform is scalable; if delivered at a population level with may help reduce the prevalence of dementia globally.

#### **Keywords**

Prevention, Cognitive decline, lifestyle, brain training, physical activity, nutrition, depression, anxiety



### A world Alzheimer month turned towards prevention, sport and dementia

#### Mrs Lorène Gilly

France Alzheimer et maladies apparentées, Paris, France

#### **Topic**

Dementia risk reduction: Dementia and sport

#### **Abstract**

In 2023, for World Alzheimer Month, France Alzheimer and related diseases organized 3 main events at the national level:

Our first MEMORUN: to gather the general public, people living with dementia and their families around a sportive and festive event.

A "Village Alzheimer" on the race site, one of the biggest park in Paris, to welcome runners and the general public, to inform, raise awareness and for everyone to try adapted physical activities.

A conference: "Sport and brain: risks, prevention and benefits". Sport is often associated with good health but there are still risky practices inherent to certain sports and talking about it is essential.

On the 20th of September, around 500 people attended this conference. Following scientific studies and decisions made by other Federations in Europe, it appeared relevant to explore this issue, related to primary prevention. It is essential to:

- understand the effects of certain risky practices on health;
- to inform and offer users solutions to practice their favorite sports in the best possible conditions.

Programme of the conference:

Introduction to neuroprogressive diseases: brief and educational presentation of how brain works and its dysfunction during a neuroprogressive condition;

Is the practice of sport without risk to our health? Feedbak and testimonies from athletes, explanation of trauma cranial injuries and concussions;

Sport, shock and neuroprogressive condition: what science says;

What do the main Federations think? Round table of the French rugby and boxing Federations (The French football Federation declined their presence at the last minute);

Towards an adapted practice of physical activities. Sport on prescription: what sport offers to keep us in good health and what France Alzheimer proposes to people living with dementia and their caregivers.

#### **Keywords**

Prevention, Alzheimer, dementia, sport, brain, risk reduction



The association between time-use in physical activities, to watching, and sleep with cognitive performance among middle age and older adults: a cross-sectional isotemporal substitution analysis.

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** Sedentary behavior, especially TV-watching, is a risk factor for accelerated cognitive decline, whereas physical activity is considered a protective factor. The objective of the present study is to estimate the influence of time reallocation of TV-watching to diverse physical activities and sleep on cognitive performance.

**Methods:** A cross-sectional study using baseline data of Lifelines Cohort study, restricted to participants aged ≥40 years (n= 58,686). Cognitive performance was assessed with the Ruff Figural Fluency Test. The average time (minutes/day) in TV-watching, sleep, and physical activities (active commuting, leisure, sports, household, and work activities) was calculated using self-reported questionnaires. Isotemporal substitution models were applied to examine the reallocation of TV-watching (30 minutes/day) with other activities. Analyses were adjusted for potential confounders and stratified for sleep duration (short, normal (7-8hours/day), long) and age (40-59 years, ≥60 years).

**Results:** Among participants with normal sleep (75%), TV-watching time was inversely associated with cognitive performance in middle aged ( $\beta$  (95%CI): -0.31 (-0.42 to-0.21) and older ( $\beta$ (95%CI): -0.32 (-0.52 to-0.14) participants. Replacing 30 minutes of TV-watching with leisure ( $\beta$  (95%CI): 0.26( 0.17 to 0.34), sports ( $\beta$  (95%CI): 0.57 (0.46 to 0.67), household ( $\beta$  (95%CI): 0.24 (0.13 to 0.31), or work ( $\beta$  (95%CI): 0.43 (0.34 to 0.51) activities had beneficial effects on cognition, while the reallocation for sleep was inversely associated with cognitive performance ( $\beta$  (95%CI): -0.34(-0.65 to-0.04) among middle-aged adults. Among older adults, only reallocations of TV-watching time with leisure, sports and work activities showed beneficial effects on cognitive performance. For the short and long sleep group, results were slightly different.

**Conclusions:** Adults who spent more time at watching TV had on average a lower cognitive performance. Strategies to engage middle aged and older people for physical activities as alternative for TV-watching may hold promise for slowing age-related cognitive decline.

#### **Keywords**

isotemporal substitution analysis, executive functioning, physical activity, sedentarism, sleep, middle-age adults, older adult population.



### "Never too early. Never too late": Strategies used to make an impact in Brazil

**Dr ELAINE MATEUS**<sup>1</sup>, Miss Ana Lucia Gomes<sup>2</sup>, Mr Daniel Thomas<sup>1</sup>, Mr Renan Simplicio<sup>1</sup> <sup>1</sup>Febraz, Londrina, Brazil. <sup>2</sup>Febraz, Porto Alegre, Brazil

#### **Topic**

Dementia risk reduction: Public health campaigning

#### **Abstract**

Awareness campaigns play a pivotal role in public policy strategies concerning dementia. The World Health Organization, in its "Global Action Plan on the Public Health Response to Dementia 2017-2025," recognizes campaigns as one of the seven vital action areas dedicated to enhancing the quality of life for individuals with dementia, their caregivers, and the broader community. In 2023, Febraz took the initiative in Brazil for the "Never Too Early, Never Too Late" campaign, developed by Alzheimer's Disease International (ADI). The campaign's core theme revolved around risk factors, emphasizing their impact on brain health, even in the post-diagnostic stages.

During this presentation, our objective is to share our experience and highlight the impact of the campaign ran in September 2023, with 1-month follow-up. A multifaceted approach was adopted, encompassing in-person events, social and traditional media, and collaborative efforts with partners to disseminate messages to society, healthcare professionals, people living with dementia, and their families.

Measurements include a survey, a log of activities and engagements, and Google Analytics. While gauging outreach is fundamental, our focus also delves into the strategies employed to engage diverse groups. We explore the methods applied to ensure the message resonates across various social strata, fostering a more inclusive and informed society regarding dementia risk reduction.

#### **Keywords**

national campaign, risk reduction, contextual strategies



# The Cognitive Kitchen: A codesigned nutrition program pairing evidence-based eating strategies and lifestyle habits with socialization to support dementia risk reduction and living well with dementia

**Dr Allison Cammer**, Ms Julie Beitel, Dr Norma Stewart, Mrs Edna Parrott, Dr Megan O'Connell University of Saskatchewan, Saskatoon, Canada

#### **Topic**

Dementia risk reduction: Dementia and nutrition

#### **Abstract**

Using principles of codesign and patient-oriented research, a group of researchers, clinicians, and persons with lived experience developed a culinary nutrition intervention pairing evidence-based eating strategies and lifestyle habits with socialization to support dementia prevention and living well with dementia. The resultant program, The Cognitive Kitchen, for older adults, care-partners and persons living with dementia is 6 weeks with in-person or virtual 2-hour sessions held weekly. Sessions include an overt educational component (nutrition and dementia risk reduction and health promotion strategies), a culinary demonstration and participation in preparing 2 or more recipes, a covert educational component (health at every size, emphasizing abilities, 'all foods fit', cook once-eat twice, self compassion), and socialization activities. Each session centers on a theme; 'Nutritious, Delicious, Connection' outlines the role of nutrition in health and the importance of connection during mealtimes, 'Bringing Science to the Table' focuses on the nutrition risk-reduction evidence and counters myths, 'To Taste' highlights flavour and texture for enjoyment and how to maximize flavour for health, 'To Share' emphasizes the importance of socialization and strategies to incorporate social connection through food, 'Minute-Meals and Kitchen Tips' outlines meal preparation with limited time and kitchen organization for safety and convenience, and 'Around the World' discusses age-friendly and dementia friendly strategies and Blue Zones (areas of the world with greater longevity). A Registered Dietitian coordinates and facilitates the sessions, enabling each program to be tailored to the particular health needs of the participants. This presentation describes the codesigned program and 'lessons learned' through initial evaluation efforts.

#### **Keywords**

dementia, nutrition, risk reduction, codesign, culinary intervention



## Effects of an Empowerment Intervention on Enhancing the Collaboration and Well-being of People with Younger Onset Dementia and Their Care Partners

**Ms Bel WONG**<sup>1</sup>, Dr Kenny CHUI<sup>1</sup>, Dr Lisa AU<sup>2</sup>, Miss Tobi CHENG<sup>1</sup>, Mr Kingsley PUN<sup>1</sup>, Ms Florence HO<sup>1</sup>, Prof Timothy KWOK<sup>1,2</sup>

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#### **Topic**

**Dementia research and innovation:** Younger onset, Mild Cognitive Impairment (MCI) and mild dementia

#### **Abstract**

**Aim:** People with younger onset dementia (PwYOD) and their care partners (CP) need to work collaboratively and closely to handle the physical, psychological, financial, and legal challenges after diagnosis, however, the existing cognitive-training-focused intervention model does not cater this need. This study is to evaluate the effects of an innovative empowerment intervention model on facilitating the collaboration between PwYOD and their CPs to enhance their well-being.

**Method:** This study adopted a single-arm, prospective cohort study design. A 6-month empowerment intervention based on the collaborative recovery model was developed by Jockey Club Centre for Positive Ageing supported by the funding of The Hong Kong Jockey Club Charities Trust to facilitate PwYOD and their CPs to establish an alliance collaboratively on needs identification, goal setting, and goal attainment monitoring, under a case management approach. The study outcomes were caregiving experience (Positive Aspects of Caregiving), perceived family support of PwYOD (Family APGAR), and goal attainment (Goal Attainment Scale); they were measured at baseline and post-intervention. Paired t-tests were performed to measure within-subject changes after intervention, univariate regression was performed to identify factors associated with the outcomes.

**Results:** The pretest-posttest evaluation of n=30 PwYOD and their CPs showed a significant improvement in CP caregiving experience and its sub-domain of "enriching life" of CPs, in the perceived support from CP of the PwYOD, and in the capability of goal attainment of the PwYOD and their CPs. Univariate regression results showed that post-intervention perceived support from CP of PwYOD and goal attainment was associated with functional status such as fall risk and functional disabilities.

**Conclusion:** The preliminary findings of this study affirmed the effects of this empowerment intervention on facilitating the collaboration and enhancing the well-being of people with younger onset dementia and their care partners. Further studies on factors affecting the outcomes should be conducted.

#### **Keywords**

younger onset dementia, collaborative recovery model, positive aspects of caregiving, perceived family support, goal attainment



## We don't fit: research into the experience of navigating health and social services and support for children with dementia and their families.

Ms Gail Hilton, Ms Megan Maack, **Dr Kristina Elvidge** Childhood Dementia Initiative, Sydney, Australia

#### **Topic**

**Dementia research and innovation:** Less common dementias and syndromes (including Down Syndrome and childhood dementia)

#### **Abstract**

**Background:** Childhood dementia results from progressive brain damage caused by over 70 rare genetic disorders. Most children die before turning 18. Childhood Dementia Initiative (CDI) partnered with Nous Group to conduct research to articulate the 'lived experience' of families in their interactions with care and support services and identify the key challenges.

**Methods:** Semi-structured interviews were conducted via Zoom; interviews were recorded with the consent of participants and transcribed using Otter. Key themes were identified using thematic analysis.

**Results:** Eight parents (8 mothers, n=5 caring; n=3 bereaved) consented to participate in an interview. Six themes emerged: 1. Conditions that cause childhood dementia are rare, difficult to diagnose and diverse, which results in delayed diagnosis, 2. Following diagnosis, there is no defined clinical pathway and parents find it difficult to navigate health services and supports to meet their child's needs, 3. Parents become project managers for their child's care, experiencing a high administrative burden, 4. Paediatric palliative care fills a necessary navigation and coordination gap but is not consistently accessed, 5. NDIS packages are an essential support for families, but are universally challenging to access and manage, 6. Following the death of their child, families need targeted, ongoing support.

**Conclusion:** Families living with a child with dementia state they 'do not fit' in current care and support structures. This research will enable advocacy and systemic change driven by CDI to ensure appropriate, equitable and high-quality care for families affected by childhood dementia in Australia.

#### **Keywords**

childhood, children, care, research, systems, advocacy, lived experience



### Stand by Me - Experiences of couples with intellectual disability when one partner has dementia

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<sup>1</sup>University of Stirling, Stirling, United Kingdom. <sup>2</sup>University of Edinburgh, Edinburgh, United Kingdom

#### **Topic**

**Dementia research and innovation:** Less common dementias and syndromes (including Down Syndrome and childhood dementia)

#### **Abstract**

**Aim:** People with intellectual disabilities are at increased risk of dementia at an earlier age. At the same time, individuals are living longer and enjoying greater quality of life, including relationships and marriage. Stand by Me is the first study to explore the experiences of couples with intellectual disabilities when one partner has a diagnosis of dementia. The need for the study was identified by a married man with an intellectual disability and dementia who remained an integral part of the UK research team.

**Method:** Life story interviews were conducted with five people with intellectual disability whose relationship was, or had been, affected by dementia. Other participants were nine social care professionals and four family members with experience of supporting the couples, or one of the partners. When combined, this produced data from eight couples that was thematically analysed.

**Results:** The eight couples had been together for a combined total of 170 years; the longest relationship lasting 20 years. Themes were identified of support for, and disruption to, relationships; making sense of the dementia diagnosis; partners with intellectual disability as informal care partners, and lack of involvement in decision making.

**Conclusions :**The inclusion, equality and empowerment of people with an intellectual disability varies globally, with stigma ever present due to misconceptions of ability even before a diagnosis of dementia. Stand by Me demonstrated that couples with intellectual disability can continue to enjoy loving and intimate relationships after one of the partners receives a diagnosis of dementia. However, additional and unique challenges were faced that were different to couples affected by dementia who did not have an intellectual disability. Longer life expectancy means that more people with intellectual disabilities will be living with dementia. It is therefore important to understand the complexities, and to ensure that both partners receive appropriate support.

#### **Keywords**

intellectual disability, Down syndrome, couples. relationships



### Impact of COVID-19-RelatedLockdown on Psychosocial, Cognitive, and Functional Well-Being in Older Adults With Down Syndrome

**Dr Emanuele Rocco Villani**<sup>1</sup>, Prof Graziano Onder<sup>2</sup>, Dr Antonella Di Paola<sup>1</sup>, Prof Davide Liborio Vetrano<sup>3</sup>, Dr Cecilia Damiano<sup>4</sup>, Dr Angelo Carfi<sup>1</sup>

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#### **Topic**

**Dementia research and innovation:** Less common dementias and syndromes (including Down Syndrome and childhood dementia)

#### **Abstract**

**Introduction:** People with Down Syndrome (DS) experience younger-onset dementia. With the outbreak of CoVID-19 pandemic, strict social isolation measures have been necessary to prevent the spreading of the disease. Effects of this lockdown period on behavior, mood and cognition in people with DS have not been assessed so far.

**Aims:** In the present clinical study, we investigated the impact of CoVID-19-related lockdown on psychosocial, cognitive and functional well-being in a sample population of 46 adults with DS.

**Methods:** The interRAI Intellectual Disability standardized assessment instrument, which includes measures of social withdrawal, functional impairment, aggressive behavior and depressive symptoms, was used to perform a three time-point evaluation (two pre-lockdown and one post-lockdown) in 37 subjects of the study sample, and a two-time point evaluation (one pre- and one post-lockdown) in 9 subjects. Two mixed linear regression models – one before and one after the lockdown – have been fitted for each scale in order to investigate the change in the time-dependent variation of the scores.

**Results:** In the pre-lockdown period, significant worsening over time (i.e., per year) was found for the Depression Rating Scale score ( $\beta$  = 0.55; 95% Cl 0.34; 0.76). In the post-lockdown period, a significant worsening in social withdrawal ( $\beta$  = 3.05, 95% Cl 0.39; 5.70), instrumental activities of daily living ( $\beta$  = 1.13, 95% Cl 0.08; 2.18) and depression rating scales scores ( $\beta$  = 1.65, 95% Cl 0.33; 2.97) was observed, as was a significant improvement in aggressive behavior ( $\beta$  = -1.40, 95% Cl -2.69; -0.10).

**Conclusions:** Despite the undoubtful importance of the lockdown in order to reduce the spreading of the CoVID-19 pandemic, the related social isolation measures suggest an exacerbation of depressive symptoms and a worsening in functional status in a sample of adults with DS. At the opposite, aggressive behavior was reduced after the lockdown period.

#### **Keywords**

Down Syndrome, COVID-19, mood disorders, BPSD





### Adapting Alzheimer's Disease Modifying Treatment Criteria to Accommodate Adults with Down Syndrome

**Dr Matthew Janicki**<sup>1,2</sup>, Mr Hampus Hillstrom<sup>3</sup>, Dr Richard Fisher<sup>3</sup>

<sup>1</sup>University of Illinois Chicago, Chicago, USA. <sup>2</sup>National Task Group on Intellectual Disabilities and Dementia Practices, Rockport ME, USA. <sup>3</sup>LuMind IDSC Foundation, Burlington MA, USA

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

The recent approval in the USA of anti-amyloid immunotherapeutics (e.g., Legembi) for treating adults with early-stage sporadic Alzheimer's disease (AD) has raised concerns about the exclusion of adults with neuroatypical conditions, such as Down syndrome (DS) and other intellectual disabilities (ID), due to wording of prescribing criteria. Patients with DS/ID are implicitly not covered by the prior authorization criteria for these therapies, potentially depriving them of access to a beneficial treatment. To address this, an international expert panel was convened and asked to recommend modified prescriber criteria, ensuring their suitability for DS/ID patients once the drugs are deemed safe for use with this group. Many patients with DS/ID show younger age dementia onset and floor effects on AD diagnostic assessments, compared to adults with sporadic AD. Recommendations to prescribing criteria included lowering the age of eligibility (<50), using alternative measures for diagnosis and neurocognitive decline relevant to DS/ ID (specialized DS/ID instruments), broadening latitude in presentation due to lifelong cognitive limitations (recognizing behavioral variants), and raising clinician proficiencies in diagnosing dementia in adults with DS/ID (continuing education). The work of the expert panel led to a rise in awareness of the issue and to a directed advocacy effort undertaken with federal officials to arrive at an agreement to achieve equity in access. Given the universality of barriers for assessing adults with neuroatypical conditions for dementia, the USA exercise and its results has value for many countries undertaking determinations of approval for new AD disease-modifying therapeutics.

#### Keywords

Disease modifying treatments, Down syndrome, intellectual disability, Alzheimer's drugs, diagnosis, assessment



### The importance of palliative care in late-stage dementia: Looking through caregivers' eyes

**Mr Thanos Chatzikostopoulos**, Mrs Anastasia Neokosmidou, Miss Nena Gakoudi, Mr Vasilis Stamos, Mrs Filio Anagnostopoulou, Mrs Panagiota Giannakopoulou, Prof Magda Tsolaki

Greek Association of Alzheimer's Disease and Related Disorders, Thessaloniki, Greece

#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

Palliative care is a specialized type of medical care that aims to improve the quality of life for patients with serious illnesses and it is provided by an interdisciplinary team of healthcare professionals. Palliative care for people with dementia is an area of increasing importance because it can improve the quality of their life by managing symptoms, such as pain, agitation depression and other challenging behaviors, and providing emotional support to them and their families.

The Greek Association of Alzheimer's Disease and Related Disorders created the first unit of palliative care for people with dementia in late stages in Greece. The goal of the unit is to provide holistic and personcentered care to its residents. To succeed it, different means are used, such as reminiscence therapy, the Montessori approach, different coping strategies for the management of behavioral symptoms, Snoezelen and psychological support to the caregivers. However, a key factor to this direction is the help and the cooperation with the caregivers who are valuable partners in our efforts. The present study examines the attitudes and the beliefs of caregivers regarding the provided palliative care with a structured interview and their feelings regarding the absence of their beloved people from the house. These data are also supported from their responses in Zarit Burden Interview (ZBI) (p< .05), Centre for Epidemiologic Studies Depression Scale (CES-D) (p<.05) and Marwit-Meuser Caregiver Grief Inventory - Short Form (p<.05). Moreover, their opinions regarding the needs of a person with late-stage dementia and the support from the national healthcare system are mentioned. With all these data, new information and useful special guidelines for palliative care on late stages of dementia will be discussed.

#### **Keywords**

palliative care, caregivers, late-stage dementia



#### Enhancing post-diagnostic support in Australian memory clinics: Current practices, and barriers and facilitators to the provision of desirable support

**Mrs Sladana Pavkovic**<sup>1</sup>, Dr Lyn Goldberg<sup>1</sup>, Prof Sharon Naismith<sup>2</sup>, Prof Perminder Sachdev<sup>3</sup>, Dr Jane Alty<sup>1</sup>, Dr Melissa Abela<sup>1</sup>, Prof Lee-Fay Low<sup>2</sup>

<sup>1</sup>Wicking Dementia Research and Education Center, University of Tasmania, Hobart, Australia. <sup>2</sup>The University of Sydney, Sydney, Australia. <sup>3</sup>University of New South Wales, Sydney, Australia

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Introduction:** Memory clinics (MCs) provide specialist assessment services for people experiencing cognitive symptoms or other changes which may indicate a diagnosis of dementia. There is little information about the post-diagnostic support provided in MCs across Australia.

**Aim:** To explore the perspectives of health professionals and people with living experience of dementia regarding current practices, and barriers and facilitators to the provision of desirable post-diagnostic support in MCs in Australia.

**Methods:** In a cross-sectional qualitative exploratory study, data were collected from health professionals through five focus groups (n = 22) and two expert panel meetings (n = 22) between October 2020 and November 2021. Individual interviews were conducted with 13 people with dementia and 17 care partners between September 2021 and October 2022. Reflexive thematic analysis was undertaken.

**Results:** Professionals, people with dementia and care partners described **current post-diagnostic practices** as: *Tailored communication and feedback about diagnosis*; *Prescription about medication and follow-up*; *Referrals to health and community services*. **Desirable support** was described by two themes by both groups: *A single point of post-diagnostic support*, and *Education and information*. However, health professionals additionally discussed two additional desirable support ideas: *Cognitive interventions in memory clinics* and *Counselling*. In terms of **barriers**, both groups said *The whole system hinders post-diagnostic support*. Additionally, people with dementia and care partners said that a **facilitator** to post-diagnostic support was *Family support*.

**Conclusion:** People with dementia and care partners primarily rely on family support. Memory clinics currently do not provide desirable post-diagnostic support. Structural changes associated with Australian government investment are required to improve support for people with dementia and care partners.

#### **Keywords**

Dementia, post-diagnostic support, memory clinics, people with dementia, care partners, health professionals, Australia



### Structured Support for Persons with Dementia and their Next of Kin after Diagnose - An Intervention Study

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Mid Sweden University, Sundsvall, Sweden

#### **Topic**

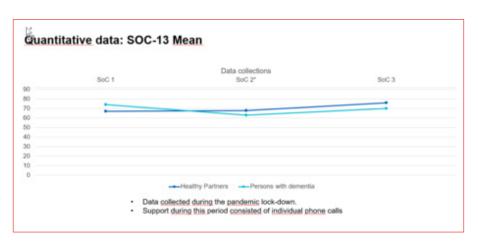
**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Aim:** The aim of this study was to implement a structured support for people with dementia and their family soon after diagnosing, with the intent to increase quality of life and enabling aging in place for people with dementia. Specific research questions were, could support in support groups soon after diagnosing maintain or increase quality of life as measured by SOC-13? Would support groups enable persons to live in their own home for longer?

**Method:** Staff af support centres was given training in PER-model® of support before enrolling participants to support groups. A mixed method was used with interviews of participants as well as SOC-13 questionnaire. Data were collected during winter of 2019/2020-spring 2022.

Results: Qualitative results; Interviews were analysed with content analysis on a manifest level. Two categories were identified: Sharing common experiences with subcategories, Talking about problems and Meeting others in the same situation. Second category was Feeling safe in a group with subcategories; Having access to expert help and Being in my own group. Statistical data of SOC-13 shows that persons with dementia started off with slightly higher scores of SOC-13 than their family member. During the



pandemic lockdown the SOC-13 scores lowered for persons with dementia but increased slightly for their family member. Both increased their SOC-13 scores when the support groups started up again (see attached PNG file).

**Conclusion:** Structured support groups seems to increase quality of life, both in persons with dementia and their immediate family. Participants were still living at home, unaided, after the intervention.

#### **Keywords**

Dementia, Intervention, support



### Neurorehabilitation of people with dementia.Gotcha! an app-based therapy for proper name anomia in people with dementia

#### Miss Aygun Badalova

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

Proper name anomia is a common experience that can become amplified in patients with a diagnosis of dementia (PWD). The Gotchal app aims to provide practice-based therapy for PWD to relearn the names of key people in their lives. It has been developed according to the principles of errorless learning, which have previously been shown to improve the remembering the familiar people's names and benefit the relationship between the PWD and their loved ones. (Clare et al. 1999, 2000, 2003).

**Methods:** Gotcha! is a digital confrontation naming therapy app which enables patients to train one face per day by using photos that the app represents. During the development phase we carried our qualitative research (thematic analysis) on why PWD get involved in research projects such as ours. Gotcha! therapy block lasts for six weeks and prior to the therapy patients complete a multiple baseline paradigm with eight weekly tests of free naming of the to-be trained faces. During the therapy, a novel speech verifier is used to provide real-time feedback (Barbera et al. 2020).

**Results:** The thematic analysis revealed four themes that will be discussed in more detail on the talk. In terms of the quantitative data, our results from the first 20 subjects showed: 1) Tau-U. 80% showed a positive trend with better naming during the training phase with 8/17 reaching statistical significance. 2) ANOVA demonstrated a significant effect at the group level of training>baseline phase, F(1,9) = 6.68, p = .029.

**Conclusion:** App-based proper name anomia retraining works for the majority of PWD in our trial thus far. Being able to freely recall and produce the name of a relative or loved one has a big impact on people's lives.

#### **Keywords**

neurorehabilitation, proper name anomia, people with dementia, alzheimer's



### Inequalities in care, treatment and support trajectories for people with dementia and family carers (STRiDE England)

#### Ms Adelina Comas-Herrera

London School of Economics and Political Science, London, United Kingdom

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Aims:** The STRiDE England project explores how current national policies and their local implementation affect the experiences, health and wellbeing of people with dementia and their unpaid carers and how social care, primary care, public health, social protection and community support systems (the 'dementia system') mitigate or exacerbate inequalities in access to care and support.

**Methods:** The study was organised in two phases. Phase 1 involved formative research to identify the key issues that affect the experience of people with dementia or those providing unpaid care. This included Theory of Change workshops with people with dementia and carers, a rapid review of literature on inequalities in dementia, and an in-depth situational analysis of the policies and systems for dementia. In phase 2 we are carrying out interviews (n=48) with people with dementia and unpaid carers in four localities in England, chosen to maximize variation of the sample and to allow examination of how different people's characteristics and those of where they live affect how different people experience 'dementia system'. Based on emerging findings from the analysis, focus groups will be held with professionals delivering and commissioning dementia care and support services to analyse the experience of local study participants from a local services perspective and identify opportunities for local and national systems improvement.

**Outcomes:** The project will analyse the dementia care and support system at macro, meso and micro levels, using individual experiences as the lens through which to analyse the system. A roadmap will be developed to demonstrate how to improve care and support for people with dementia and carers by making recommendations for change at both local and national levels. People with dementia, carers and professionals will advise at every stage.

#### **Keywords**

Dementia care, inequalities, care trajectories, care pathways, local care systems, dementia care ecosystems, access to care, care pathways



## Pilot Study of the Avia Pervia nurse + OT home program for people living with advanced dementia and their caregiver, provided by the center for cognitive disorders and dementia in Modena, Italy

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Health Authority and Services of Modena, Modena, Italy

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Introduction:** Advanced dementia poses complex challengees for people with dementia (PWD) and their caregivers (CG), requiring a personalized multidisciplinary approach. This study aims to investigate the feasibility of implementing an integrated telemedicine and home care program within Memory Clinic provided by nurses and OT. This program is designed to support care at home and is based on two existing programs: the Care Ecosystem and the Care of Older Persons in their Environment.

**Materials And Methods:** The Avia Pervia Nurse + OT program is built upon a thorough analysis and assessment of the individual needs of PWD and their CG, taking environmental factors into account. Using a combination of teleconsultation and field visits, the nurse case-manager provides specialized nursing care and health monitoring, while the OT delivers targeted interventions to improve behavioral aspects and participation of the PWD. The program will be applied to 10 PWD-CG dyads, and the outcomes will be assessed using various scales.

**Expected Results:** during this 2-month intervention period, quantitative and qualitative data will be collected to evaluate the effectiveness of the intervention. Assessment scales employed will include the Goal Attainments Scale (GAS) for specific goals, the Quality of Life in AD (QoL-AD) for both PWD and CG, the NPI for behavioral disturbances, the Short Sense of Competence Questionnaire (SSCQ) for CG's sense of competence, and the Zarit scale for CG stress. This pilot study will provide evidence regarding the feasibility of the program and the sensitivity of the scales used. The results will influence the future development of the protocol and assessment for the care of PWD and their CG, laying the groundwork for an efficacy study.

BIBLIOGRAPHY Gitlin, Laura N., et al. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. Jama 304.9 (2010): 983-991.

#### **Keywords**

Case management, occupational therapy, dementia care



# A systematic mapping review of 525 randomised controlled trials on pharmacological and non-pharmaceutical interventions for people living with dementia and their formal and informal caregivers in Chinese communities

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<sup>1</sup>Lingnan University, Hong Kong, Hong Kong. <sup>2</sup>Austrian National Public Health Institute, Vienna, Austria. <sup>3</sup>The University of Hong Kong, Hong Kong, Hong Kong

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Aims:** Over 20% of people living with dementia being from Chinese communities, while best-practice recommendations for dementia are mostly based on evidence generated in western countries. This study aims to synthesize the evidence on the effectiveness of interventions for individuals living with dementia and their caregivers in Chinese communities worldwide.

**Methods:** We conducted a systematic review to map interventions for individuals living with dementia or mild cognitive impairment and their caregivers in Chinese communities (registered on PROSPERO: CRD42019134135). We searched two widely-used Chinese databases (China National Knowledge Infrastructure, WanFang DATA) and eleven English bibliographical databases (MEDLINE, EMBASE, PsycINFO, CINAHL Plus, Global Health, WHO Global Index Medicus, Virtual Health Library, Cochrane CENTRAL, Social Care Online, BASE, MODEM Toolkit, Cochrane Database of Systematic Reviews), supplemented by manual searching of reference lists. Randomized controlled trials (RCTs) assessing intervention effectiveness among the Chinese population, published between January 2008 and June 2020, were included for synthesis. RCTs were evaluated for quality using the Cochrane risk-of-bias tool for randomized trials (version 2). A narrative approach was performed.

**Results:** Of the 53,041 studies identified, 525 unique RCTs were included for synthesis. The interventions studied encompassed a wide range, with multi-component interventions comprising 35% of the studies, followed by pharmacological interventions (30%), non-pharmacological interventions (18%), and traditional Chinese medicine (14%). Among the included RCTs, 93% were published in Chinese. The majority focused on cognition and functional status of people with dementia, while only a few studied the interventions for caregivers. Over 80% of the included RCTs were judged to have "some concerns".

**Conclusions:** This study highlights significant gaps in evidence concerning interventions for dementia in Chinese communities. The findings contribute to shaping the understanding of existing evidence and provide valuable information for practice, policymaking, and further research in the field of dementia care in Chinese populations.

#### **Keywords**

Dementia intervention, Systematic review, Chinese communities



#### Promoting timely diagnosis of dementia with free BrainTrack app

#### Ms Kelly E Burns

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#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

BrainTrack, a free app developed by Dementia Australia, aims to promote brain health self-awareness, privately monitor cognitive well-being, and encourage help-seeking regarding subjective cognitive concerns among individuals who want to explore more about their brain health and track any cognition changes over time. The app, which has been downloaded more than 56,000 times since its launch in October 2022, presents a unique travel-themed narrative where users embark on virtual journeys to different countries, engaging in eight interactive games that simulate common travel activities. Each game specifically targets cognitive domains such as memory, planning, and language comprehension, fostering engagement and is completed monthly.

While BrainTrack is not intended as a validated diagnostic tool, it draws from validated cognitive assessments to offer a general indication of the cognitive processes that may be affected in dementia. Users can download an 'Insights Report', allowing them to observe their cognitive performance over time. The report is designed to facilitate confidential brain health discussions between general practitioners (GPs) and their patients, supporting timely diagnosis and intervention.

This presentation will share the findings and data derived from the more than 17,000 BrainTrack users who opted into complete user surveys, shedding light on how a simple yet captivating app can contribute to the timely diagnosis of dementia. The results obtained from the app's implementation will provide valuable insights into its potential as a supportive tool for healthcare professionals and individuals seeking to proactively monitor and address cognitive health concerns.

#### **Keywords**

Dementia, diagnosis, brainhealth, games, application



## Co-developing An intelligent UbiquiTOus solutioN fOr MultimOdal daily living procedUreS tracking in people with dementia (AUTONOMOUS): insights from participatory design research

Miss Inês Silva<sup>1</sup>, Mr Filippo Talami<sup>1</sup>, Miss Joana Couto<sup>1</sup>, Miss Britt Pellens<sup>2</sup>, Miss Ana Vasconcelos<sup>1</sup>, Miss Lieke Lenaerts<sup>2</sup>, Mr Ricardo Graça<sup>1</sup>, Mr Hugo Gracio<sup>1</sup>, Prof Mayank Goel<sup>3</sup>, Prof Andrea Wilkinson<sup>2</sup>, Prof Niels Hendriks<sup>2</sup>, **Prof Cristina Mendes-Santos**<sup>1</sup>

<sup>1</sup>Fraunhofer Portugal AICOS, Porto, Portugal. <sup>2</sup>LUCA School of Arts, Genk, Belgium. <sup>3</sup>Carnegie Mellon University, Pittsburgh, USA

#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Background:** Dementia is a neurodegenerative condition that significantly impacts the ability of individuals to perform activities of daily living (ADL), challenging their independence. Human activity recognition (HAR) intelligent solutions may support People with Dementia (PwD) in tracking and completing ADLs, but research on the topic is limited. AUTONOMOUS, an international project focusing on the co-development of a HAR intelligent solution composed of a smartwatch and a smartphone app for PwD and their significant others (primary users) and a web app for formal caregivers (secondary users), bridges this knowledge and supportive care gap.

**Aim:** This communication aims to share with the community the insights arising from participatory design research conducted in the context of AUTONOMOUS and how such insights were used as inspirations during the solution's co-development. A further aim is to reflect on how these insights impact other innovations targeting PwD.

**Method:** We will base our presentation on AUTONOMOUS' case study and draw on the different immersive and relational participatory design methods used during the solution's co-development.

**Results:** We will provide a detailed account of our methodological processes and findings and discuss how participatory research insights gathered among various stakeholders (i.e., PwD, their significant others, healthcare professionals, data protection officers, and decision-makers) influenced the development of the solution. We will also reflect on the implications of such methods and findings on the development and uptake of innovations targeting PwD.

**Conclusions:** By discussing AUTONOMOUS co-development, we expect to foster research and development of HAR intelligent solutions targeting PwD, promoting their independence.

#### **Keywords**

Dementia, Assistive Technology, Human-activity recognition, Artificial Intelligence, Participatory Design



#### Keeping active with gaming: What works for people with dementia?

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<sup>1</sup>University of Toronto, Toronto, Canada. <sup>2</sup>KITE, Toronto Rehab Institute, Toronto, Canada. <sup>3</sup>University of Reading, Reading, United Kingdom

#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Introduction:** Exercise video games (i.e., 'exergames'), or games you play by moving, can encourage people living with dementia to engage in more physical activity, which could lead to better health outcomes. Commercially available gaming systems and exergames can be accessible to people living with dementia. However, more information is needed about what makes these systems and games accessible for people living with dementia, taking into account their cognitive difficulties.

**Objective:** To explore what works for people living with dementia when introducing new exergames to widen access to physical activity.

**Methods:** Using the talk-aloud protocol, thirty-two people with dementia (mean age: 78.25 years; 56.25% female; mean MoCA: 12.75/30) participated in group 'game testing sessions' once per week for six weeks at four community-based adult day programs. Each session introduced a different commercial exergame system, including the Nintendo Wii, Xbox Kinect, and Nintendo Switch and a selection of games. Video-recorded observations and participant feedback were collected during each gameplay session for analysis.

**Results:** Preliminary findings confirm that the talk-aloud protocol is useful for collecting immediate feedback from people with dementia. Individuals can identify what they like and dislike in games and when using the exergame systems. This is supported by an analysis of the video data highlighting ingame prompts and controller usability issues.

**Conclusions:** In this study, the talk-aloud protocol empowered people living with dementia to give feedback on what they like and dislike about currently available exergames and gaming systems. These findings can help design new exergames to increase access to physical activity for people with dementia. The findings will also be of interest to dementia service providers who would like to use exergames to increase physical activity for people living with dementia.

#### **Keywords**

Dementia, gaming, physical activity, accessibility



### Porta-D: Immersive experiences for anxiety in people living with dementia.

Mr Camilo Fonseca, Mr Steven Grisales

Porta, Bogotá, Colombia

#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

PORTA D is a mobile solution containing non-pharmacological therapies for anxiety in people living with dementia, in the form of interactive and immersive virtual reality experiences that can be used at home. It combines breathing techniques, binaural audio in located specific frequencies, and natural therapeutic and familiar environments simulated in virtual reality. PORTA D captures the user's breathing and converts it into data that not only helps to monitor our immersive therapies and improve their use; but also allows timely diagnoses and recommendations using A.I. by analyzing breathing patterns and biometrics.

PORTA D - Is made for Smartphones/Cardboard Glasses and Meta Quest.

Anxiety is a common symptom among people affected by dementia. It can manifest in a variety of ways, such as agitation, restlessness, fear, difficulty sleeping, eating, and communicating with others.

Through VR immersive experiences and breathing techniques, PORTA D generates neuroplasticity in the brain using simulated therapeutic environments. Our goal is to improve the health, wellness and quality of life of people affected by dementia related anxiety through disruptive, low-cost technology and a non-pharmacological approach.

Meditation is probed as a solution for anxiety, but meditating is quite difficult for people diagnosed with dementia. PORTA D solves the difficulties that advanced meditation demands, providing the user with an easy-to-use tool that will help them improve their quality of life.

By Co-designing with people affected by dementia we will use A.I. to replicate familiar environments made from old photos or videos, and use familiar voices as the spoken guide within the immersive experiences; establishing a digital bridge between the person affected by dementia and their relatives and an extra feeling of soothing reminiscence while using Porta-D.

Our Data Collection from users and Machine Learning models will turn PORTA D into an at home diagnosis solution for Alzheimer's and Dementia.

#### **Keywords**

dementia, anxiety, Virtual Reality, Artificial Intelligence, breathing technics, reminiscence, diagnosis, binaural audio, frequencies, portable, data collection, machine learning, biometrics, smartphones



#### Enhancing the Use of Sound in Dementia Care Through Participatory Development of Sound-based Technologies: The Technology Box Approach

Mrs Patrizia Held, Ms Ulrike Lindwedel

Furtwangen University, Furtwangen, Germany

#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Aim:** In dementia care, sound interventions often take a back seat to music, despite their potential importance. This study, part of the DIDEM project funded by the Carl Zeiss Foundation, explores the untapped potential of digital sound solutions using the innovative Technology Box method. This approach aims to familiarise people with the technology they are going to improve or create.

**Methods:** In a comprehensive exploration of technology-based sound solutions, we provided various commercially available sound technologies (e.g. icho therapy ball, inmu sound pillow, Qwiek.up, Resono soundpad, Bluetooth speakers) to three care facilities for testing. Each facility received a box containing the technology, a simple manual and a diary. The caregivers were tasked with integrating the technology into their daily routines, with no specific instructions on how to use it. They observed participants, asked basic questions about the technology, and documented the sessions.

**Results:** The Technology Box method allowed us to assess the needs of people living with dementia and their caregivers for sound technologies, particularly during the COVID-19 pandemic when access to the field was limited. It effectively introduced sound and music-based technologies to caregivers and people living with dementia, fostering a deeper understanding of their role in the research process and the technical solutions to be developed based on their experiences. This approach also significantly improved caregivers' understanding of the preferences and needs of people living with dementia. Furthermore, it is evident that people living with dementia are indeed capable of independently using technical artefacts that are relevant to them.

**Conclusion:** The Technology Box approach offers a practical way to introduce interactive technologies to both caregivers and people living with dementia. As we explore the intersection of technology and healthcare, innovative methods such as the Technology Box pave the way for more inclusive and effective solutions to dementia care.

#### **Keywords**

dementia care, digital sound interventions, sound-based technologies, technology box method



### Utilizing Machine Learning and Computer Vision for Early Detection of Dementia Through Facial Features

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<sup>1</sup>Stockholm University, Stockholm, Sweden. <sup>2</sup>Department of Psychiatry, University of Oxford, Oxford, United Kingdom. <sup>3</sup>Department of Engineering, University of Oxford, Oxford, United Kingdom

#### **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Introduction:** Dementia continues to pose a critical challenge to healthcare systems globally. Current understanding suggests that the pathogenesis leading to dementia begins years or even decades before the manifestation of cognitive symptoms. Early identification of individuals at risk can significantly improve therapeutic interventions, offering an opportunity to mitigate or even reverse Alzheimer's pathology—the predominant cause of dementia. This study aims to explore the potential of facial features as diagnostic and predictive biomarkers for early-stage dementia using advanced machine learning algorithms.

**Methods:** We have developed the Cognes smartphone application to facilitate data collection for this study. A total of 200 participants will be recruited, with equal distribution of gender, consisting of a control group and individuals with a clinical dementia diagnosis. Each participant, or their authorized carer, will provide baseline demographics such as age, sex, and diagnosis. They will also capture a facial photograph using the application and submit retrospective facial photos dating back 10 years. The primary objectives include conducting a diagnostic biomarker assessment and a predictive biomarker evaluation. Advanced machine learning algorithms will be utilized to analyze the collected data.

**Expected Results:** Our primary objectives are dual-faceted: 1) to conduct a diagnostic biomarker assessment, and 2) to perform a predictive biomarker evaluation. We employ machine learning techniques to rigorously evaluate the utility of facial features as both diagnostic and predictive biomarkers for dementia. Preliminary data suggests that facial features undergo subtle but distinct changes as dementia progresses, thereby indicating their potential utility as biomarkers.

This research introduces a new avenue for dementia detection by leveraging facial features, a hitherto unexplored data source. By optimizing machine learning algorithms to analyze this novel form of data, we aspire to contribute to the evolving landscape of dementia diagnosis and care, offering new pathways for timely interventions and improved healthcare outcomes.

#### **Keywords**

Dementia, Early Detection, Machine Learning, Computer Vision, Facial Features, Digital Biomarkers, Alzheimer's Disease, Diagnostic Biomarker, Predictive Biomarker, Non-Invasive Methods





### Arterial diameter changes in the brain and improvement of olfactory and cognitive functions post olfactory therapy in MCI

**Prof Rona K Graham**<sup>1,2</sup>, Ms Melissa Lessard-Beaudoin<sup>1,2</sup>, Mr Marco Perez Caceres<sup>1</sup>, Ms Laura Martinez Gonzalez<sup>1,2</sup>, Prof Tamas Fulop<sup>1,2</sup>, Prof Dominique Lorrain<sup>1,2</sup>, Prof Kevin Whittingstall<sup>1</sup>

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#### **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

**Background:** There is a substantial gap between the burden of neurodegenerative diseases and the resources available to prevent and treat them. Research efforts that aim to develop preventive therapies are of ever-increasing importance. Evidence suggests that olfactory therapy may improve olfactory functions and importantly affect functional connectivity networks and lead to restoration of neural circuits.

**Method:** The aim of our study is to evaluate the olfactory system (olfactory tests and MRI of olfactory brain regions) and cognition levels (cognitive function, episodic memory, executive functions, and language) in control and MCI individuals at baseline, one year later (pre olfactory therapy), and post olfactory therapy.

**Results:** Baseline measurements reveal the presence of deficits in olfaction, odor memory and several cognitive functions in the MCI individuals. Our results also identified medications that impact olfactory function. Furthermore, an increase in average tortuosity of the middle cerebral artery and a decrease in the diameter of the anterior communicating artery were observed in the MCI compared to controls. In contrast, post olfactory therapy, our data show improvements in the smell identification, global cognition (MoCA), verbal learning, visuospatial memory, and cognitive flexibility scores. Differences were also observed in the middle cerebral artery diameters between pre and post olfactory therapy.

**Conclusion:** Despite extensive evidence showing olfactory system dysfunction is observed in MCI there have been no investigation of olfactory memory, and limited studies of olfactory training as a therapy. Our results show that olfactory therapy may provide benefit for individuals with MCI and, to some extent, control individuals.

#### **Keywords**

Mild Cognitive Impairment, olfaction, cognition, olfactory therapy, MRI



## Addressing fear and inspiring hope: Results from a randomized control trial to reduce fear of dementia and improve well-being among community-based older adults

**Dr Francesca R Farina**<sup>1,2</sup>, Ms Hosanna An<sup>1</sup>, Ms Melissa Marquez<sup>1</sup>, Dr Marc Bennett<sup>3</sup>, Prof James W Griffith<sup>1</sup>

<sup>1</sup>Northwestern University, Chicago, USA. <sup>2</sup>Trinity College Dublin, Dublin, Ireland. <sup>3</sup>University College Dublin, Dublin, Ireland

#### **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

**Aim:** Alzheimer's disease and related dementias are among the most feared conditions, especially among older people. High levels of fear are detrimental to well-being and can lead to harmful avoidance behaviors such as delayed help-seeking. Fear also perpetuates stigma and hopelessness, which negatively affects people living with dementia. Our aim was to assess whether a brief (3-week) psychological intervention could reduce fear of dementia and improve mood, social functioning, and quality of life in older adults.

**Methods:** Participants were randomized to experimental or control groups. All participants completed psychoeducation and tailored mindfulness modules specific to dementia. The experimental group completed an additional behavioral activation module designed to promote adaptive coping with fears. Data were analyzed using linear regression models adjusted for age, sex, and anxiety.

**Results:** Participants were 81 older adults ( $65.3 \pm 7$  years; 71.6% female) experiencing high levels dementia-specific fear. We found that fear decreased significantly over time in both groups (B = -6.63, p < .001). Participants also reported fewer memory failures (B = -1.63, p = .008) and less anxiety and depression symptoms (Bs > -1.64, ps < .039). Depressive symptoms were lower in the experimental group compared to the control group. Participants also reported improvements in well-being (B = .60, p = .006) and greater ability to participate in social activities (B = 2.34, p = .007) post-intervention.

**Conclusions:** Addressing fear is vitally important to inspiring hope and eradicating the pervasive stigma surrounding dementia. Our results show that tackling fear through a brief psychological intervention can improve mood, social participation, and well-being in older adults who are highly fearful of dementia. This has important implications for healthy aging and lifestyle risk reduction. By addressing fear, interventions like this one can help to promote help-seeking and continued participation in activities that are protective against dementia.

#### **Keywords**

Fear, Avoidance, Intervention, Older, Anxiety, Depression, Social, Well-being





# Valuing dance practice among people living with dementia: insights from research and the community

#### Ms Magda Kaczmarska

Global Brain Health Institute, San Francisco, USA. DanceStream Projects, New York, USA. Foundation Dementia Action Alliance Poland, Gdańsk, Poland

#### **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

Dance is an art form increasingly recognized for its role to promote lifelong brain health and wellbeing in part through community engagement coupled with physical fitness. A growing body of evidence illustrates the protective effects of dance on brain health among older adults: engaging motor function, supporting wellbeing, offsetting depression, and offering ameliorative cognitive effects. For people living with dementia, dance centers dignity and meaning and extends resources for engagement and connection at a time when other forms of communication might be limited. Stories in the Moment is an evidence-informed dance, movement and collaborative storytelling program that centers the expressive voices of people living with dementia and care partners, while extending their resources for meaningful communication. This program applies known benefits of dance on multiple domains of brain health for older adults and people living with dementia by balancing dance activities led by the facilitator with individual and group improvisational dance. This form of engagement and the resulting co-created dance stories (miniature dance performances) emphasize existing modes of communication, while heightening awareness and utility of the coupling of verbal and embodied expression. The collaborative dance practice which grows out of this engagement amplifies and extends agency, personhood and meaningful connection while building new spaces of belonging. This interactive presentation will review existing research on the connection of dance and brain health, offer examples of how this research can be translated into dance practice through sample activities from Stories in the Moment, and feature preliminary results from research supported by funding from GBHI, Alzheimer's Association, and Alzheimer's Society (GBHI ALZ UK-22-865612) from a pilot study on the benefits of dance to support wellbeing and a sense of belonging among people living with dementia and care partners through an online delivery of the Stories in the Moment dance program.

#### **Keywords**

dance, embodiment, dementia, neuroscience, movement, brain health, arts and health, community arts practice, wellbeing, non-pharmacological interventions



# Developing immersive gamification technology systems for the management of behavioral and psychological symptoms of Alzheimer's disease dementia (Phase 2 trial)

**Dr Veeda Michelle Anlacan**<sup>1,2</sup>, Dr Roland Dominic Jamora<sup>1,2</sup>, Ms Isabel Teresa Salido<sup>3,2</sup>, Mr Angelo Cedric Panganiban<sup>4,2</sup>, Mr Bryan Andrei Galecio<sup>5,2</sup>, Prof Maria Eliza Aguila<sup>6,2</sup>, Dr Cherica Tee<sup>7,2</sup>, Dr Michael Tee<sup>8,2</sup>, Prof Jaime Caro<sup>4,2</sup>

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#### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

#### **Abstract**

**Background:.** Behavioral and psychological symptoms of dementia constitute a major component of the dementia syndrome and are strongly correlated with cognitive and functional decline. Virtual reality (VR) therapy is a non-pharmacological intervention currently being explored in the management of Filipinos living with dementia, due to its potential to enhance reminiscence and induce nostalgia through personalization and cultural adaptation within a realistic virtual simulation of an experience. A local pilot study among healthy adults has shown that a VR intervention induced mild to no VR sickness, was positively received, and was easy to use by the participants.

**Aims.** The study aims to expand upon the results of the prior study by testing a VR intervention among persons with mild to moderate Alzheimer's disease (AD) with behavioral and psychological symptoms.

**Methods.** A clinical trial among 30 patients with mild to moderate AD with behavioral and psychological symptoms is being conducted: 15 patients will be randomly allocated to test a head-mounted display (HMD) system and the remaining 15 patients will be assigned to test the semi-cave automatic virtual environment (semi-CAVE) system. The clinical trial participants will test the VR intervention for four sessions held once a week for four weeks. The primary outcomes for assessment include clinical effectiveness (Neuropsychiatric Inventory-12), safety (Virtual Reality Sickness Questionnaire) and usability (System Usability Scale); cognition (Montreal Cognitive Assessment – Philippines, Mini-Mental State Exam, cognitive subscale of the Alzheimer's Disease Assessment Scale), activities of daily living (Alzheimer's Disease Cooperative Study - Activities of Daily Living Inventory) and quality of life (health-related quality of life for people with dementia) will also be assessed as secondary outcomes.

Results. Recruitment and data collection for the clinical trial will be completed by January 2024.

#### **Keywords**

immersive gamification, virtual reality, dementia, behavioral and psychological symptoms of dementia



Creating the First Scottish Dementia Arts festival, a collaborative project between the ideas fund and Deepness Ltd a peer run dementia organisation in the Outer Hebrides, an ethnographic research project following people with dementia & "carers" as artist participants from the Highlands and Islands attending hybrid meeting centres.

Mr Ronald Coleman<sup>1</sup>, Ms Kirsten Broadfoot<sup>2,3</sup>, Ms karen Taylor<sup>1</sup>

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#### **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

"And we Watched as Directors Danced
Poetry in Motion
And The members Painted, Sculpted and Drew
And Installations were made
And the Children Played
And the Members Sang and Took photos
Boys will be Boys as They Contrived new Conversations
And How Everyone Laughed
And Weavers Weaved a tapestry Of Tales
Songs Were Sung, Tales Were Told Films Were Made
Women Renewed our Communities Divine Splendour
And Crafty Crofters Created Crafted Delights one more Time
And A Demented festival was Born
..."

Ron Coleman 2022

The goal of our project is to create an arts festival which shows how participating in creative activities people living with dementia and their supporters specifically, their agency, autonomy and mental wellbeing. Our arts festival will be held in November 2023 and will first have a local showing in Stornoway before heading to Inverness. At the festival, we will present our art, processes and our stories of our artistic journeys alongside each other to show how life with art impacts our wellbeing.

#### **Keywords**

dementia, Arts, creativity, festivals, , peer support, music, film, living with dementia, peer run,



# Co-production of a non-pharmacological intervention for tailored management of sleep disturbances in people living with dementia

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#### **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

People living with dementia often experience sleep disturbance, which can affect their daily functioning and wellbeing. Prescription sleep medication is often relied on by clinicians and patients alike to manage sleep problems but has known associated adverse effects. Efforts to tackle problematic polypharmacy have proposed use of advanced generalist medicine to better deliver tailored care. Our study examines application of these principles to managing specific issues associated with sleep disturbance in this group. TIMES is a five-year NIHR funded research programme in the UK which aims to develop deliver and evaluate a novel intervention supporting tailored whole-person treatment of sleep disturbances in people living with dementia. Using advanced generalist principles of care, we present our non-pharmacological intervention for assessment and management.

We conducted a realist review of the literature, observations of tailored care in practice and mininterviews with clinicians. We also conducted focus groups with people living with dementia, their family members and primary care providers to identify key factors required for delivery of tailored care. Further discussion with Patient and Public Involvement groups and expert-led co-production workshops have identified core components for a non-pharmacological intervention for tailored management of sleep for people living with dementia. Vignettes capturing typical features of care journeys, and potential approaches were used for co-development. Our intervention aims to deliver a tailored assessment and understanding of how to optimise the whole-person management of sleep disturbance in people living with dementia, to be used by clinicians, people living with dementia and their families in the primary care setting.

#### **Keywords**

dementia, sleep, tailored-care, person-centred care, whole-person, holistic, primary, non-pharmacalogical interventions, qualitative



# Integrated care for older people with dementia in Thai communities: a multisite study.

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

The rising number of dementia prevalence globally causes many countries' care system fall. Community is a new hope for a better sustainable service. The World Health Organization (WHO) introduces Integrated Care for Older People (ICOPE) guidelines as a method to deliver a community-based care system. Will it practical under Thai context?

**Aim:** A three-year longitudinal study with two research projects aimed to explore the feasibility of integrating WHO: ICOPE guideline to synergize dementia care service in community-dwelling older citizens, and develop innovations supporting these services in Thailand.

**Method:** In the first year, ICOPE screening tool was implemented to identify cognitive impairment in 3 settings, 70,000 participants. In the second year, healthcare needs will be gathered to develop a tailored health-services. Then, in the third year, the sustainability of the innovative service will be investigated.

**Result:** Of the total population, approximately 50% of participants were screened, indicating high prevalence of cognitive impairment. Based on ICOPE domains, cognitive impairment was associated with various functional declines, particularity mobility, vision, and hearing impairments. The new innovative health-service platforms—ICOPE data management, speech cognitive screening application, and Thai dementia holistic care website to support caregivers—demonstrated both practical and acceptance.

**Conclusion:** ICOPE guidelines is practical not only screening, but also developing new innovations to improve person-centred care for people with dementia. Notably, cognitive impairment may have more profound impact beyond expectation, particularly in older adults. Further research is imperative to explore the acceptability and knowledge dissemination via novel platforms in various contexts.

#### **Keywords**

care model, care platform, community, dementia, ICOPE, WHO, Integrated Care for Older People, screening, innovation, carer, support



# Promoting quality of life through integration of palliative care and advance care planning for older adults in Qatar

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#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Background:** Advance care planning (ACP) for older adults specifically people living with dementia and their carers is underutilized. ACP, an essential patient-centered process in palliative care, enables individuals with life-limiting illnesses to identify core values, goals and personal preferences for care. ACP is crucial to improving quality of care and overall wellbeing.

**Methods:** A needs assessment to integrate palliative care into the care of elderly in Qatar included literature review, review of program data, key informant interviews, patient and caregiver surveys and nurse and physician surveys.

**Results:** The study included 33 key informant interviews, 100 surveys with older patients, 102 surveys with family caregivers and 141 surveys with nurses and physicians. 97% of patients and caregivers had never heard of advance directives. Only 78% of caregivers agreed that it was important to inform the patient about diagnosis and treatment options, while 100% of patients reported wanting to be informed. The majority (93%) of patients and caregivers agreed that patients have the right for the final say in decision-making, while 47.5% of caregivers and 57% of patients agreed that patients have the right to refuse medical treatment in matters of life and death. For DNAR orders, 55% of patients and 41% of caregivers agreed that patients have the right to choose DNAR in the event of arrest. Key informants described several challenges to ACP and end of life discussions including overprotective families, families' fear of guilt and psychological impact of truth telling and delay in diagnosis of dementia.

**Conclusion:** A holistic approach to integrating ACP as part of palliative care into the healthcare system, with special attention to older adults with dementia is recommended. This includes developing a national culturally sensitive framework for truth telling and ACP, enacting national laws and policies, developing national awareness raising campaigns and training healthcare providers.

#### **Keywords**

palliative care, advance care planning, dementia



# The meaning of a good death among people living with dementia in the UK and in Brazil: Opportunities for culturally-sensitive approaches in palliative dementia care

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#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Aim:** Few studies to date have directly asked people living with dementia (PLwD) about their views regarding a good death taking into account their diagnosis or compared their perspectives cross-culturally. The aim of this study was to compare the meaning of a good death for PLwD in Brazil and the UK.

**Method:** A convenience sample of 32 PLwD (16 each in Brazil and the UK) took part in semi-structured interviews between Jul 2019 and Aug 2021. A co-developed topic guide was used in both countries. We assessed all participants for cognitive capacity to give informed consent. Two teams of interdisciplinary researchers independently analysed transcripts for their country, using inductive thematic analysis, followed by jointly developing overarching themes on the contrasts and similarities across the two countries.

**Results:** We identified three shared themes: choice and control; spirituality; and fears and wishes. Choice and control permeated all aspects of what a good death meant to PLwD in the UK but was largely absent from Brazilian narratives. The opposite was true for spirituality, which was central to the meaning of a good death in Brazil, while far less prominent in the UK, even among religious participants. Fears and wishes was the only theme showing substantial similarities between the two countries, although notable differences were also observed in that regard. The way participants experienced and assuaged fears was predominantly related to spirituality in Brazil, and choice and control in the United Kingdom.

**Conclusions:** Our results have potential to expand the awareness and sensitivity of health and social care professionals around different cultural views on what a good death means for PLwD and what helps or hinders achieving it. Such cross-cultural comparisons offer new opportunities for designing culturally-sensitive approaches to palliative dementia care.

#### **Keywords**

dementia, death, palliative care, cross-cultural comparisons, qualitative research



# A family affair: interviews with people with dementia and an active euthanasia wish and their families

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#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Aim:** To examine the motives of people with dementia who desire euthanasia with a special focus on reasons related to family or relationships. In addition we aim to assess how family of people with dementia experience their situation and responsibilities and how this might change.

**Method:** Fourteen interviews were conducted including interviews repeated with three years in-between. People with dementia and an active euthanasia wish were interviewed, and three years later, two of them and five family members were interviewed again.

**Results:** Family is an important factor in the motivations for a euthanasia wish for people with dementia. In pre-liminary thematic analyses by two researchers, we found four themes: (1) Protecting the relationship from the impact of dementia affecting it; (2) Family as primary setting to discuss euthanasia; (3) Obviousness of the family member's agreeing with the euthanasia wish; (4) Experienced responsibilities.

**Conclusion:** People with dementia and a euthanasia wish describe a fear of becoming a burden, losing their identity and losing control over who they are in the eyes of loved ones and that this will negatively affect their relationships. The wish for euthanasia for people with dementia can fade overtime due to relational reasons or a better quality of life than anticipated when first diagnosed. Family members self-evidently support the euthanasia wish but struggle how to account for it if euthanasia is no longer a legal option due to diminished capacity. The wish for euthanasia and the advanced directive can create a moral burden for family members, which the persons with dementia are unaware of.

#### **Keywords**

euthanasia, PAS, physician assisted suicide, dementia, family, ethics,



# **Enjoying Life with Dementia - My first Ocean Swim**

#### **Mr William Michael Yeates**

Dementia Alliance International, Sydney, Australia. Dementia Australia, Sydney, Australia

#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

As a progressive neurological disease, the diagnosis of Alzheimer's Disease brings with it a multitude of challenges that impact on every aspect of your life. These encompass cognitive issues (memory loss, behavioural changes, and your ability to carry out daily tasks), as well as social, emotional, physical, psychological, and financial challenges. As a result, over time, there is a significant change in the quality of life that you can experience post diagnosis.

Having been diagnosed with Younger Onset Alzheimer's Disease in August 2019 at the age of 59, this presentation is about the change in quality of life that I experienced when I decided to step out of my comfort zone and participate in my first ocean swim in Fiji. To overcome the barriers that I encountered in order to achieve this goal, I created my own Reablement Plan that consists of five steps – Person-centred Assessment, SMART goal, Developing your Plan, Implementing your Plan and Evaluation. Particular attention is given not only to the organisers of this event but also the role that Allied Health specialists played in the development of a Neuro Cognitive Training Program that was instrumental in achieving this goal.

In presenting my Reablement Plan I hope to encourage others who are also living with dementia, to explore ways that they can enjoy a better quality of life – one that you value and has meaning. I also hope that my presentation helps to change people's perception about this disorder.

#### **Keywords**

challenge yourself, SMART goals, Reablement, quality of life



# Exploring the benefits of an early and timely diagnosis of dementia? Data from the DETERMIND Programme

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#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** Global policy directives advocate an early or 'timely' diagnosis of dementia. Whilst the potential benefits of this approach have been widely discussed, there remains a dearth of empirical studies examining this important area. Drawing on data from DETERMIND, a prospective cohort study of people recently diagnosed with dementia, we explored the benefits and harms of an early or 'timely' diagnosis of dementia on Quality of Life (QoL) and well-being of people with dementia and their care partners in England.

**Method:** We examined baseline DETERMIND data on 935 people newly diagnosed with dementia in the previous six months and 698 care partners. 'Early diagnosis' was defined temporally ( $\leq$ 24 months between onset of first symptoms and diagnosis) as well as based on dementia severity at entry to the study (Clinical Dementia Rating  $\leq$  1). 'Timely diagnosis' was defined using carer's and person with dementia's subjective reports of timeliness. A series of regression models examined the association between these indices and outcomes related to QoL, well-being, anxiety, and care burden.

**Results:** There was little agreement between indices on what was considered early or timely. Whilst early diagnosis indices were associated with improved outcomes, these typically did not reach statistical significance. Carer reported timeliness was consistently associated with significant positive carer outcomes (p<0.05). The same benefits were not observed for people with dementia, with only a single outcome (QoL) being statistically associated with the person with dementia's reported timeliness (p<0.05).

**Conclusion:** How we conceptualise when someone is diagnosed, whether that is early or timely, has implications on outcomes. Most benefits are associated with carers, particularly when they perceive the diagnosis to be timely. Dementia policies and practice should encourage and support a timely diagnosis that is right for both the person with dementia and the carer.

#### **Keywords**

Dementia diagnosis, timely diagnosis, early diagnosis, quality of life, well-being



# Living alone with cognitive impairment in Sweden

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#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aim:** Older adults with cognitive impairment (OACI) are less likely to use health care services and are at risk for malnutrition, self-neglect, falls and fires. OACI have poorer health outcomes and have a greater number of unmet needs such as financial, medications and mobility. In Sweden it is estimated that 44 percent of persons who receive a cognitive diagnosis live alone in a community setting. Research from OACI's and other perspectives are limited. Therefore, the aim is to design a study capturing different perspectives of living alone with cognitive impairment in a community setting in Sweden.

**Method:** This study is part of a multi-centred research project. Earlier research indicates the presence of ethical concerns in respecting the wishes of OACI to maintain independence while perceived needs of support are present. To create a study protocol for a Swedish context, a group of experts, academics and health and social care professionals has been formed to discuss a cultural adaption of the study with researchers from UCSF who have completed a similar study in USA.

**Results:** Through qualitative interviews investigate how OACI describe management of their cognitive impairment in the context of living alone, resources relevant to them, ethical dilemmas arising from living alone with cognitive impairment and the meaning of having a neurocognitive diagnosis. This is the first of four studies focusing on different perspectives of living and supporting OACI living alone in a community setting. Study II will focus on perspectives of OACI who co-habitate, study III focuses on home care personal perspectives and study IV on perspectives of social care planners' responsible for decision making for support and care offered. The findings of this study can help gain better understandings of the needs of OACI and identify ways to address needs and improve quality of life

#### **Keywords**

Dementia, cognitive impairment, community setting, living arrangement, older adults.



# Advancing Health Equity: A Memory Care Unit in a Large Public Nursing Home

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#### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

#### **Abstract**

Studies show access inequities to high quality, end-of-life palliative care in the US, based on race, ethnicity and socioeconomic status with low ratings for satisfaction, communication, and pain management. As racial-ethnic minorities are the fastest growing segment of our elderly population, these inequities will worsen if actions are not taken to address it now. Health systems and its care teams in the long-term care setting, along with policy makers, must understand its root causes, including key psychosocial determinants of health and acquire the knowledge to implement corrective strategies, based on existing innovative care models like the memory unit which will be featured in this program.

The large New York City public nursing home, with a two-thirds racial-ethnic minority population, will demonstrate how this innovative care model can be successfully applied to advance equity in access to high quality, end-of-life palliative care for this population. It will discuss the root causes, including long-range planning/development, leadership structures/systems, staff training, communication strategies, person-centered, interdisciplinary care planning, novel behavioral health interventions, the role of clinical ethics, and key quality metrics. We will present 3 illustrative case studies. Upon completion, participants will be able apply this approach in similar settings.

Our goal is to enable long-term care health care systems and providers to incorporate key aspects of our innovative care model via implementation of policy changes, based upon a best practice interdisciplinary care team strategy which can be measurably shown to boost team morale and improve patient/family satisfaction. By utilizing this approach, current practices can be improved by setting achievable goals, verifiable by quality metrics, with improvement in key areas, such as reductions in antipsychotic usage and tube feeding in advanced dementia, increased enrollment in palliative care, reduction of non-beneficial treatments for those with life-limiting illness and decreased hospital transfers.

#### **Keywords**

Health equity, palliative care, memory care



# Rights, equality and dementia advocacy: Time for a new script

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#### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

#### **Abstract**

People living with dementia are routinely denied their human rights at individual, community, and societal levels. This lack of equal status is being challenged nationally and internationally as people with dementia speak out. They bring the language of human rights, equality and social justice to dementia policy and practice. Helen Rochford Brennan, Global Dementia Ambassador, maintains that people living with dementia face new barriers to realising their rights as a result of their dementia diagnosis. The Assisted Decision-Making Act in Ireland is a case in point. Underpinned by the Convention on the Rights of Persons with Disabilities (CRPD), this Act places a duty on the Irish Government to maximise a person's capacity to make decisions. Yet, the practical implementation of this right to decision making is undermined by inequalities in resources in the health and social care sector. It also reflects the unequal resources necessary to address the various barriers that deny active participation. Realisation of this right is also curtailed by stigma which is driven by a largely medicalised dementia discourse. It denies people with dementia equal recognition in society. Moreover, the right to engage in equal decision making is weakened by the fact that the voice of the person with dementia is not often heard in public or policy discourse, which means they are lacking equal representation. In this scenario, realising rights is directly shaped by equalising the conditions of people's lives in terms of access to equal resources, recognition, representation, and relations of care.

#### **Keywords**

rights, equality, advocacy, voice, UNCRPD



# Alzheimer's Associations in Mexico: current challenges and moving forward

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#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

During the COVID-19 pandemic, as in most parts of the world, Alzheimer's Associations in Mexico adapted and modified most of the services they offered, not only having to change in person to virtual services but rethinking their scope and outreach strategies. In addition, it made clear that there is an urgent need to move from a basic assistance focus relying on public funds, to proactive fundraising, large scope associations. As new evidence on the impact of modifiable risk factors of dementia and the chance to work towards timely optimal detection new opportunities also arise to develop programs and support services and materials.

In this context, we generated a policy brief as part of the STRiDE: Strengthening Responses to Dementia in Developing Countries, a multi-country study carried out in Brazil, Jamaica, South Africa, India, Indonesia, Kenya, and Mexico from 2018-2022. We will present the main challenges and recommendations included in the policy brief, including actions to increase awareness around dementia, actions to work on risk reduction and prevention, and large in person and online actions towards eliminating stigma in the general public as well as among government officials, health care providers and other service providers. In addition, it will cover specific recommendations for associations in Mexico to participate in research projects, as they support the increase of knowledge on dementia and dementia care in the country which in turn can be used in policy and practice in the future.

#### **Keywords**

Mexico, dementia policy, advocacy, associations, care support



# Emerging Drug Treatments for Early Alzheimer's Disease and Suggested Global Prices Based on a Model-based Cost-Effectiveness Analysis

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#### **Topic**

Dementia as a public health priority: Economics of dementia

#### **Abstract**

Introduction: Numerous disease-modifying treatments (DMTs) for early Alzheimer's disease (AD) are progressing through phase II and III trials, marking significant AD therapeutic advancements. The U.S. Food and Drug Administration (FDA) has accelerated approval for two amyloid-targeting treatments, Aducanumab and Lecanemab, and is assessing Donanemab despite ongoing clinical and economic effectiveness controversies. However, their extremely high prices in the US market (\$28,200 for Aducanumab and \$26,500 for Lecanemab annually) and the lack of coverage elsewhere raise global accessibility and affordability concerns. This study, therefore, aims to conduct a cost-effectiveness (CE) analysis of the three mentioned DMTs to recommend global pricing based on country-level CE thresholds.

**Methods:** We constructed a five-state Markov model (i.e., MCI due to AD, Mild, Moderate, Severe and Death states) to estimate the CE of the three mentioned DMTs compared to usual care over the lifetime horizon. To allow direct comparison of trials with different outcome measures, we incorporated crosswalks between the measures. We employed country-level CE thresholds to estimate global pricing points. Robustness for the model was assessed using probabilistic sensitivity and scenario analyses.

**Expected Results:** This ongoing cost-effectiveness analysis will present estimated outcomes including discounted costs, quality-adjusted life years (QALYs) and incremental CE ratios (ICER) for three DMTs in the U.S. as a base case and then adapt to other countries. Threshold analysis will estimate the optimal pricing points which will be summarised in a table for reference.

**Conclusion:** Our findings are expected to reveal significant price disparities based on global country-level CE thresholds. Thus, there is a crucial need to implement pricing policies tailored to the country level to tackle affordability and inequalities in patient access worldwide.

#### **Keywords**

Economic evaluation, Cost-effectiveness analysis, global prices, pricing, Alzheimer's Disease, Dementia



# Global estimates of amounts of informal care 2019 of people with dementia in 194 WHO member states

**Prof Anders Wimo**<sup>1</sup>, Dr Katrin Seeher<sup>2</sup>, Dr Rodrigo Cataldi<sup>2</sup>, Mr Oskar Frisell<sup>3</sup>, Prof Linus Jönsson<sup>1</sup>, Dr Tarun Dua<sup>2</sup>

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#### **Topic**

Dementia as a public health priority: Economics of dementia

#### **Abstract**

Background: Most people with dementia are cared for by family members or other unpaid caregivers.

**Methods:** A systematic review on hours of informal care.

**Results:** 89,373 million hours of informal care were spent in ADLs in 2019 (5.2 hours per day (h/d)). If supervision-time is included the number reaches 133,255 million hours (7.8 h/d). In high-income countries, the average number of hours is 4.5 h/d (7.6 with supervision-time), while in low-income countries, it reaches 8.0 h/d (11.7 with supervision-time. The global hours correspond to 45 million full-time workers (67 million with supervision-time). Relation to dementia severity: ADLs: 3.8 h/d in mild (5.6 with supervision-time), 5.8 in moderate (9.1 with supervision-time) and 8.3 in severe dementia (12.4 with supervision-time)). Women's contribution to care provision is about 70%.

**Conclusions:** The burden of informal care is substantial, particularly for women. Given the predicted increase of dementia cases, every country needs a comprehensive response to address dementia.

#### **Keywords**

Dementia, Alzheimer's disease, informal care, unpaid care, economics



# Limitation in access to care of patients with dementia in Cameroon : How to address it ?

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#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

Dementia is a major health problem in sub-Saharan Africa. The increase in life expectancy and the epidemiological transition with the emergence of cardiovascular disease contribute to the constant growth in the prevalence and incidence of this pathology. However, very few countries in this region have implemented a national program to combat dementia. This is the case of Cameroon, which has not yet equipped itself with such tools for prevention and care for patients and caregivers. This failure of our health system makes the efforts of those involved in the fight against dementia ineffective. This is why the Understanding Alzheimer's Disease Association (ACMA-Cameroon) is working boldly to involve the health authorities of Cameroon in this fight. Numerous contacts have been initiated and meetings with the authorities have taken place and are planned to demonstrate to them the seriousness of the situation. The Memory center also falls within this framework. This project, carried out by ACMA-Cameroon, aims to provide a site dedicated to diagnosis, patient care, training of health personnel and caregivers and scientific research on dementia. This will provide to leaders and public authorities reliable data to support a structured and determined mobilization. Putting all together, these actions could contribute to reversing the incidence curve of dementia in Cameroon.

### **Keywords**

Dementia, Cameroon, Memory center, ACMA



# Indigenous Peoples have dementia, too

#### Mr Michael Splaine

Splaine Consulting, Columbia, USA

#### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

#### **Abstract**

Ageing is the story of all societies and with it comes the risk of dementia and related caregiving. Indigenous peoples demographics are catching up to those of mainstream societies and the need for awareness raising and public health actions on dementia

This presentation will provide case examples of American Indian and Alaska Native tribes taking on issues with public health tactics of dementia in their own cultural voice and traditions

#### **Keywords**

Rights, Indigenous Peoples, Public Health



# The Preparedness of Germany's Healthcare System to Diagnose Individuals Potentially Eligible for a Disease-Modifying Alzheimer's Treatment

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#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

**Aims:** With the emergence of disease-modifying Alzheimer's disease (AD) treatment, concerns about health system preparedness have been voiced because of the combination of a highly prevalent disease and a complex diagnostic process. Here, we analyze Germany's capacity to identify and diagnose individuals who are potentially eligible for these treatments and to project wait times for diagnosis.

**Method:** Desk research to determine diagnostic capacity, which is assumed to be constrained for AD specialists and biomarker testing with PET scans, expert input on patient journey, and Markov model to predict wait times over 20 years starting in 2023.

**Results:** With around 18 AD specialists per 100,000 population, Germany has a higher density than the G7 average of around 10, and an average number of PET scanners with 3 per 1 million population (G7 average of 3.22). However, wait times for AD specialist appointments would reach close to 40 months and for biomarker testing around one year, in spite of an assumption that CSF analysis would be used for 95% of tests.

**Conclusions:** In spite of her robust infrastructure for memory care, projected wait times for Germany are long, albeit shorter than in England (~120 months) and the U.S. (~60 months) and similar to Sweden's. More scalable diagnostic technologies, such as digital cognitive tests and blood tests for the AD pathology to triage cases for confirmatory testing, as well as education and training for General Practitioners and specialists in private practice will be needed to avoid lengthy delays.

#### **Keywords**

Alzheimer's disease, disease modifying treatment, capacity, health system preparedness, wait times



# Finding Pesa Sooname: Using Documentary Film to Explore Selfhood and Personhood Within the Context of Dementia at the Pyramid Lake Paiute Tribe

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#### **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

Academics are increasingly studying selfhood and personhood surrounding dementia to inform care practices and community development, yet the perspectives of Native people - who are at higher risk of dementia—are scarcely considered. This presentation tells the story of a study conducted in partnership with the Pyramid Lake Paiute Tribe to unpack how tribal elders living with dementia are supported in preserving selfhood and personhood. The "Finding Pesa Sooname" project employs Video-Based Dialogical Analysis to yield both academic and storytelling outputs and, in a commitment to actively decolonizing research practices, rejects traditional research norms to support participants in sharing their stories without rigid constraints. Rather, participants are engaged in genuine conversation that helps them chart their path of perpetual becoming, elaborating their stories through generative questions instead of reducing them through fundamental truth claims. Participants described selfhood for tribal members as inextricably linked to land, family, culture, and community. Identity was so interwoven with notions of service that selfhood and personhood appeared to operate as a single construct. Tensions between Western and traditional ideologies related to these pillars of selfhood and personhood threaten the wellbeing of tribal elders living with dementia, yet participants believe intentional conversation surrounding dementia will help navigate those tensions. The term "pesa sooname" - meaning "good think" and "good thought" in Northern Paiute - resonates throughout, foregrounding the impact of positivity. Tribal members at Pyramid Lake embrace pesa sooname to support elders living with dementia and foster community well-being.

#### **Keywords**

documentary, indigenous, storytelling, qualitative, native, participatory, film, community



# Uloa, a model of care supporting people experiencing mangalo (dementia) and their carers

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<sup>1</sup>University of Waikato, Hamilton, New Zealand. <sup>2</sup>Ākiheuho, Auckland, New Zealand. <sup>3</sup>Massey University, Auckland, New Zealand. <sup>4</sup>Te Whatu Ora Counties Manukau, Auckland, New Zealand. <sup>5</sup>University of Auckland, New Zealand

# **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

The age and sex-standardised prevalence of dementia in Pacific peoples in Aotearoa New Zealand (AoNZ) is higher than that of the general population, significantly contributed to by the differential prevalence of modifiable risk factors for dementia. This higher burden of disease is not reflected in rates of diagnosis or uptake of post-diagnostic supports, with Pacific peoples more likely to be diagnosed at a more severe stage of dementia and less likely to receive funded home based support services (HBSS) or enter Aged residential care (ARC) compared to Europeans. The reasons for this are multifactorial and reflect the barriers faced by Pacific peoples throughout the dementia pathway - from societal stigma and health literacy through to systemic issues associated with access to appropriate assessment and diagnosis, and acceptable post-diagnostic services and supports.

'Ākiheuho, a Pacific health and social provider in Auckland, AoNZ, recently received funding for a 4 year grant to develop a dementia service for Pacific peoples based on the Ūloa model. Ūloa is a Pacific model of care based on indigenous ways of communal fishing that incorporates Pacific practices and worldviews into the assessment, diagnosis, and support of people with dementia and their families. In addition to this, the Ūloa model for dementia takes a societal and life course approach, incorporating community approaches to improve knowledge and attitudes toward dementia, as well as targeted campaigns for primary prevention and risk reduction.

We aim to present on our initial learnings and experiences of designing and rolling out Pacific dementia and brain health awareness campaigns in Pacific communities in Auckland, AoNZ and their impact on referral rates for dementia assessment and uptake of post-diagnostic supports.

### **Keywords**

dementia awareness, Pacific, risk reduction, community campaign



# **Driving Change: Youth-Led Dementia Advocacy in Zambia**

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<sup>1</sup>Copperbelt University Cortex Club, Ndola, Zambia. <sup>2</sup>Alzheimer's Disease and Related Dementias in Zambia, Lusaka, Zambia

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

The Copperbelt University Cortex Club, a youth-led neuroscience group in Zambia, conducted an extensive campaign during the 2023 Brain Awareness Week (BAW) to address dementia's impact and provide support to caregivers within the Zambian community.

Our multifaceted initiative featured a variety of engaging activities, including a neuron art contest, and a spirited brain bee competition involving multiple universities. These efforts collectively attracted approximately 150 participants and garnered significant media coverage.

A central element of our campaign was a thought-provoking symposium attended by 25 in-person participants and 6 virtual attendees. The symposium showcased ten speakers, including two students presenting their research through abstract posters. Discussions illuminated the considerable information gap surrounding Alzheimer's and dementia while emphasizing the crucial role of advocacy in dispelling associated stigma and societal misconceptions.

Our initiative also involved a visit to Mitanda Home for the Aged, a facility caring for over 100 dementia patients. During this visit, club members engaged in volunteer work, interacted with dedicated staff, and spent valuable time with dementia patients. Additionally, we generously donated essential resources, including food and cleaning equipment. This initiative aimed to provide club members with hands-on experience in dementia caregiving while concurrently raising awareness about the institution's commendable efforts in supporting dementia patients.

The campaign culminated in a significant public march themed "A Focus on Dementia and Alzheimer's." This impactful event, attended by a diverse range of community members, including medical students, a police escort, and a vibrant brass band, sought to educate the public and elevate awareness about these frequently misunderstood health conditions. Conversations with approximately 150 individuals from various backgrounds revealed a concerning lack of knowledge about dementia, with some attributing it to superstitions like witchcraft. Nevertheless, our club's unwavering efforts successfully dispelled these misconceptions, gradually fostering a more empathetic and informed perspective toward dementia in Zambia.

#### **Keywords**

Awareness, Advocacy, Youth, Zambia,



Transforming Dementia Care in Ukraine: challenging Soviet-era stigmatisation. This session will examine attitudes to dementia under the Soviet Union and look at the work done by NGOs, using Ukraine as a case study, in transforming attitudes and supporting those with dementia in the current context.

#### **Ms Beth Saffer**

World Jewish Relief, London, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

World Jewish Relief has been a funder of projects in support of the social cohesion and physical wellbeing of older people for over 20 years, mainly within the context of the Jewish community and predominantly in Ukraine but also in Georgia, Moldova, Belarus and Poland. Our projects are implemented by local partner organisations.

In 2015, aware of the stigma around mental health and disability which remain entrenched from Soviet times, we embarked on an ambitious programme to improve awareness and knowledge of dementia and increase opportunities for people with dementia, and their relatives, to access appropriate support. Along with a leading UK dementia organisation we conducted training on person-centred approaches, and also brought partner organisations to the UK for exchange visits.

One of the most significant challenges is tackling Soviet era stereotypes – which at best lead to fundamental misunderstandings of the causes of dementia, and at worst leads to the institutionalisation or long-term hospitalisation of people with dementia with resultant medical 'treatments' (sedation) to control behaviours as the condition progresses. Dementia is very rarely diagnosed and if it is, it happens towards the end of life stage.

Our partners have become leaders in their field. Even since the start of the full-scale invasion of Ukraine they have continued to train, support and improve awareness about dementia.

Our session will be co-presented with our Ukrainian partner organisation 'Hesed Bnei Azriel' but presented by World Jewish Relief (for language reasons) covering:

Dementia under the Soviet Union: attitudes, medicalisation, institutionalisation

Overview of the work done by World Jewish Relief and local partners in Ukraine (and Belarus, Moldova) to change attitudes to dementia: challenges and achievements

Results of an evaluation by World Jewish Relief into its dementia work and recommendations for further work in this area in Ukraine in the context of the war

#### **Keywords**

Ukraine, stigma, discrimination, awareness, person-centered approaches



# Dementia Friendly Points for integrating care services in local communities

Ms Štefanija Lukić Zlobec, Mr David Krivec

Spominčica - Alzheimer Slovenija, Ljubljana, Slovenia

#### **Topic**

Dementia awareness: Dementia friendliness and inclusivity

#### **Abstract**

Spominčica opened the first Dementia Friendly Point (DFP) in 2017, after the education about dementia for theemployees at the Office of the Human Rights Ombudsman. We have received huge interest for becoming a DFP from many different organizations. Until september 2023 more than 500 organizations: pharmacies, homes for elderly, community health centres, centres for social work, chamber of health,museums, libraries, shops, banks, post offices,Ministries and other have joined the DFP network. Spominčica started developing education programme for employees in organizations providing services accessible to public. The DFP programme consists of the training for employees, DFP opening with awareness raising content, cultural programme with local media coverage and DFP evaluation. Member organizations provide friendly and accessible use of their services for persons with dementia, share the information and knowledge about dementia in the local community and promote the dementia friendly principles.

Local communities, alongside the family, are key supportive environments where people interact, social networks are formed and basic social services operate. We found that services to support the families living with dementia exist in local communities but are fragmented. Thus it is difficult for people to get adequate support, moreover, they are often excluded from social networks and lose their supportive environment. As a response, Spominčica is implementing a 3-year Programme "Integrated dementia care in local communities", co-financed by the Ministry of Health. The main goal of the programme, that is built around the DFP's, is to activate the local environments including services providers, local authorities and NGOs to connect the existing services around families living with dementia. Moreover with the "upscaled" DFP network we aim to facilitate the inclusion of persons with dementia and their carers in local communities and stimulate their autonomy and cognitive functioning trough active involvement in activities provided by local civil society.

#### **Keywords**

dementia friendly, awareness raising, integrated care, local communities



# Dementia Advocates: Not just at seat at the table but voices influencing change

Ms Sally Lambourne<sup>1</sup>, Ms Bobby Redman<sup>2</sup>

<sup>1</sup>Dementia Australia, Sydney, Australia. <sup>2</sup>Dementia Australia, Central Coast, Australia

#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

Meaningful involvement and engagement with people with a living experience of dementia underpins the work of Dementia Australia.

Since 2021 Dementia Advocates, people of all ages living with all forms of dementia, their families, former carers, carers worked with staff to codesign the organisation's **Consumer Engagement Framework, A Stronger Voice Together**, to reflect and improve on the wide range of engagement across the organisation.

Bobby Redman, Chair Dementia Australia Advisory Committee said: "I can't begin to describe how empowering meaningful engagement is for me as a person living with dementia and knowing that the organisation is really taking what we think on board, not just ticking the boxes."

Karen Glennen, whose husband is living with dementia, said: "It's about the voices and knowledge of people living with dementia being as valued and central as people who are in a paid position within an organisation."

This presentation explores the co-design, development and impact of Dementia Australia's Consumer Engagement Framework, A Stronger Voice Together and a new supporting resource.

A Stronger Voice Together supports Dementia Australia to track, measure, improve and celebrate meaningful engagement. Collaborating with living experience experts to establish a codesign working group, define consumer engagement and identify five foundation principles known as **A.L.I.C.E.** - **A**uthentic, **L**iving Experience, **I**nclusive, **C**ollaborative, **E**mpowering. The principles are intentionally 'active' and instructional in their language. This is to centre them in the minds and work of the people who apply them most – Dementia Australia staff, Volunteers, Executive and Board.

Half the Story\_a guide co-authored by people impacted by dementia for organisations to engage in meaningful consultation with people living with dementia, their families and carers. It provides information, tips and strategies for inclusive consultation which seeks out, affirms and ratifies the voices of people impacted by dementia.

#### **Keywords**

Consumer Engagement Framework, Meaningful Involvement, Dementia Advocates, Codesign, Authentic, Living Experience Experts, Inclusion, Collaboration, Empowerment



# Transdisciplinary Collaboration to Advance Brain Health and Dementia Support in Poland: Assessing Need, Highlighting Existing Initiatives and Invoking a Call to Action

Ms Aneta Banek-Tabor<sup>1</sup>, Ms Agnieszka Cysewska<sup>2</sup>, Dr Edyta Ekwińska<sup>3</sup>, Dr Anna Janowicz<sup>4</sup>, **Ms Magda Kaczmarska**<sup>5,6</sup>, **Ms Marlena Meyer**<sup>6</sup>, **Dr Rafał Nowak**<sup>5,7</sup>, **Dr Urszula Skrobas**<sup>5,8</sup>, Ms Barbara Wrona<sup>6</sup>, Prof Polish Working Group of People Living with Dementia and Care Partners<sup>6</sup>

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#### **Topic**

Dementia awareness: Community partnerships / Public-Private-People partnerships

#### **Abstract**

Poland is one of the fastest aging countries in the European Union with an estimated 1.5 million living with dementia. These projections are expected to skyrocket, increasing 100% by 2050. Global research indicates the potential of brain health awareness and positive approaches to aging and dementia in promoting economic vitality, social solidarity and innovation. Poland lacks a National Dementia Plan and is in dire need of a universal system of prevention, diagnosis and support and a brain health awareness plan that targets all aspects of society. This proposal introduces Brain Health Poland, founded in 2023, with a mission to work collaboratively across sectors and with global partners to ensure best practices and leadership in brain health and dementia research, diagnosis and care are implemented in Poland. Brain Health Poland has 6 key action items: 1) address the education, care and support needs of people living with dementia and care partners in Poland, 2) create and distribute evidence-informed dementia awareness and brain health education to professionals and communities, 3) advocate and collaborate with local, national and international stakeholders to develop, adopt and implement a National Dementia Plan, 4) work with researchers and clinicians to lead innovation and translate global best practices within Poland, 5) work with cultural, arts and media organizations to develop national campaigns that raise awareness about dementia and brain health and disrupt narratives of loss and despair, and 6) work as allies alongside people living with dementia and care partners, ensuring their voices are heard and implemented in all decision-making processes regarding them in Poland. This presentation will include reflections from coauthors including the Polish Working Group of People Living with Dementia and Care Partners on existing systems and gaps in Poland and introduce ongoing initiatives of Brain Health Poland to address these needs.

#### **Keywords**

dementia, brain health, National Dementia Plan, person-centered approaches, advocacy, awareness, education, research



# Dance as an intervention to improve quality of life for people with dementia

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<sup>1</sup>Upplands Bro kommun, Kungsängen, Sweden. <sup>2</sup>Freelance, Stockholm, Sweden

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

People with dementia are dependent on help from relatives, friends and the community. Creating a good quality of life for people with dementia requires great commitment and also creativity. We need alternative methods and more innovation's to improve quality of live for people with dementia and one method is dance. Research shows that dance leads to well-being, increased vitality and life energy. Psychological effects such as altered behaviour and changes in stress hormones also appear. The physiological effects of dance are mainly balance, increased mobility and physical well-being. It's not just about an increased quality of life -also about being able to age with dignity.

The pandemic has caused many additional problems for families living with dementia such as loneliness, which can also be counteracted through dance.

The dancer Joakim and the gerontologist Mirjam created dancing groups for people with dementia.

Joakim and Mirjam measured the effects of their dancing project i Upplands-Bro/Sweden with "the quality of life in late-stage dementia (Qualid)" scale. The dancing sessions improved quality of life for the participations. Other results were improved strength, balance and mobility.

This workshop will introduce you to the work of an unique cooperation to improve quality of life for people with dementia and how dance can create a positive impact for the individuals.

Method: presentation, video and practise.

https://www.demenscentrum.se/nyheter?nyhet=6214 Video

Picture; Some of our dancers had the opportunity to open a conference for Queen Silvia Nursing Award with a dance performance.

#### **Keywords**

Dementia awareness and friendliness, creativity, Kooperation, dance, quality of life, grace, reduce the power of stereotypes, dementia support, inclusion



# The rise of the Memory Hubs in the UK: A model for multidisciplinary community care provision for people living with earlystage dementia and their family carers

Prof Jacqueline Parkes, Dr Alison Ward

University of Northampton, Northampton, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Introduction:** The Memory Hub Support Centres (2021-) were established through a collaboration between an NHS healthcare provider and third sector organisation. This provided a unique, best practice approach to dementia care for those newly diagnosed with dementia and their family members. The aim was to establish eight Hubs within the locality that could provide a community and health focused intervention to post-diagnostic support.

**Method:** An evaluation explored the impact of the Memory Hubs in helping to maintain the mental wellbeing, quality of life, and independence of people living with dementia and their family members. A mixed methods approach included: focus groups with members living with dementia (n=3 groups), family members (n=3 groups), and staff (n=2 groups). Interviews were conducted with key stakeholders (n=4), and a case study approach followed three paired members over one month. A desk-based review provided wider community intervention context.

**Results:** The findings demonstrate partnership organisations working collaboratively can meet the holistic needs of members. All members valued attending, learning together, and benefitting from positive social support; however, members also want separate group activities with peers. Challenges Hubs faced included supporting people to transition in/out of the service and the need for wider partnership working to support the Hubs' growth and development.

**Conclusions:** The Hubs provide a unique network of vital community resources; offering positive social support, opportunities for shared learning, friendship, reduced isolation, and enhanced self-confidence. Key lessons highlight the need for separate member activities, and staff supervision to support member transition to alternative services.

#### **Keywords**

Dementia, Memory Hub, Post diagnostic, community, intervention





# Hiking a path through younger onset dementia

#### Mr DAVID GRAY LOVELAND

Spouse, Mount Pleasant, USA

#### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

Condensing a lifetime of hiking and backpacking down to a forty-meter indoor hiking path constructed through the rooms and hallways of our downstairs floor, is vastly different from the hikes we used to lead while running an outdoor adventure company; guiding people on hikes all around the world.

However, two years after testing positive for the C9orf72 gene, my wife continues to travel down the path of younger onset dementia. Constructing an indoor "hiking trail" is just one of the adaptations we've made to allow her to continue her love of hiking and noticeably improve her experience when pacing through the house.

As her condition has progressed, we have adapted. We've gone from leading large hiking groups, to hiking by ourselves, to carrying backpacks on daily neighborhood hikes, to converting the path she paces inside the house into an indoor "hiking trail."

The indoor "hiking trail" is a little over forty meters long and is delineated by white dots spaced every eighteen centimeters. Additionally, the indoor "hiking trail" is demarcated with pieces of colored paper adorned with our grandchildren's artwork. These trail markers provide the visual stimuli necessary to result in noticeable improvements in mood, gait, and spatial awareness of her pacing experience.

Constructing an indoor "hiking trail" has provided us a trail to follow while trying to maintain a semblance of our lifetime hiking together as she continues on her path through younger onset dementia.

#### **Keywords**

Hiking, path, pacing, therapy, dementia



# A session of self-portraits in an art therapy group: An interpretive phenomenology study for persons living with moderate to advanced dementia in a facility

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#### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Aims:** This study explores how elders living with moderate to advanced dementia in the facility experienced a self-portrait session in an arts group. What are their embodiment and self-identification? How do they respond and feel through a designed art program?

**Methods:** Art making units of the body, emotion and expression give a direct experience to the one. The self-projection and the inner experience acted in the process. When an artwork is achieved, one becomes a viewer. He or she will transcend his or her self-center to be a member of the world. The art therapy reveals hidden aspects of one's Being.

A group of 9 participants with aged 65 to 80, diagnosed with moderate to advanced dementia, was conducted 90 minutes per session per week lasting for twelve weeks in a (long-term care) facility. This "self-portrait" session started with self-observation, then learned the skill through life experience. They engaged in sharing and appreciating with production. All the process was audio and video recorded. The study adopted Interpretive Phenomenological analysis.

**Results:** The themes emerged from the data analysis:1) Life experiences: Playing as catalysts for artistic skill learning. 2) Embodiment: Interacting between the inner/outer spaces of the body. 3) Self-growth: Starting from self-consciousness to self-acceptance. 4) Using animal metaphors: Exploring self-perception and perspectives on aging. 5) Mirroring-self: Operating on the mirror reaction surrounding the group. 6) Emotion expression and identification: Conveying the feelings of loneliness, tranquility, and happiness in the art making achievement process. Proactively asking, leading, and expressing ideas and actions were the key strategies for facilitating the art making group.

**Conclusion:** Findings suggest that art group implications enhance personal expressions, positive emotion, and connection with others. It provides a sense of self, collective autonomy, and personal identity. We further discussed the implications of these findings and future research suggestions.

#### **Keywords**

Art therapy, self-portrait, dementia, interpretive phenomenology



# My truth living with Primary progress Aphasia.

#### Miss Natalie Ive

Dementia Australia, Melbourne, Australia. Dementia Alliance International, Sydney, Australia. Australia Aphasia Association, Sydney, Australia

#### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

Have YOU heard of Primary Progressive Aphasia (PPA)?

PPA is a rare neurological condition that affects your ability to communicate, to express thoughts, and understand or find words. There are three PPA variants, Semantic, Logopenic & non-fluent.

No two people living with PPA are the same.

My research supports a holistic approach that places communication at the forefront of care strategies. A key component of this approach involves the collaboration of a well-supported allied health team, including speech pathologists and occupational therapists. Identifying the links between effective communication and the enhancement of safety and quality within healthcare settings. This multi-disciplinary approach ensures that individuals with PPA receive comprehensive care that addresses their unique needs, ultimately leading to improved outcomes and an enhanced quality of life.

Some days, I wake up and my speech is fine. Other days, I can hardly speak. When this happens, I use speech to text. I find talking on the telephone difficult, so I prefer to use face-to-face contact methods so that I'm able to see the person and their cues for a productive conversation.

It's challenging to listen, process information, and find the right words to respond in a conversation. This frustration leaves me feeling disempowered when the conversation has already moved on by the time I can respond. To overcome this, I've strongly advocated for raising awareness about PPA, sharing my strategies and struggles, so that I can continue working and communicating to the best of my abilities.

Many have told me, "You don't look like you have dementia." But what does dementia look like? This common phrase unintentionally perpetuates stigma and stereotypes. The words we use affect how people with dementia are perceived and treated and impacts the support, and empowerment they feel within society. Instead, let's promote understanding and inclusion.

#### **Keywords**

Primary Progressive Aphasia, Allied health care, Dementia



# Effectiveness of interventions for improving the daily function of people with dementia in Chinese Communities: a network metaanalysis of randomized controlled trials

**Dr Qi Wang**<sup>1</sup>, Dr Cheng Shi<sup>1</sup>, Dr Gloria Wong<sup>2</sup>, Dr Dara Leung<sup>2</sup>, Dr Jacky Choy<sup>2</sup>

<sup>1</sup>Lingnan University, Hong Kong, Hong Kong, <sup>2</sup>University of Hong Kong, Hong Kong, Hong Kong

#### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

Dementia is a progressive neurodegenerative disorder that poses a significant public health challenge, particularly in countries with aging populations like China. This study aimed to conduct a network meta-analysis to evaluate the comparative efficacy of various interventions in enhancing the activities of daily living (ADL) of Chinese individuals with dementia.

Using a frequentist framework, network meta-analyses were conducted to assess the effects of different interventions compared to control groups. The primary outcome was ADL in people with dementia in the Chinese community.

A total of 295 full-text articles, comprising 32,663 participants, were included in the analysis. The majority of studies were conducted in Chinese (96.61%), in a hospital setting (95.95%), and with inpatient participants (62.71%). The overall effect size was significant (SMD = 1.109, 95% CI: 0.968 to 1.251, p < 0.001). Multicomponent interventions, non-pharmacological interventions (NPI), pharmaceutical interventions, supplements and other nutrition interventions, and traditional Chinese medicine (TCM) all demonstrated significantly positive effect sizes compared to the control group. Additionally, supplements and other nutrition interventions showed a significantly positive effect compared to the placebo control group. According to P-scores, supplements and other nutrition interventions, TCM, and NPI had the highest probabilities of being the most effective interventions. Subgroup analyses indicated that the effectiveness of interventions varied depending on moderator variables.

Publication bias was detected through Egger's regression test, and the trim-and-fill method was used to correct for bias. After correction, the pooled effect size remained significant (Hedges' g = 0.50, 95% CI: 0.34 to 0.67, p < 0.001).

In conclusion, this study provides evidence that various interventions, particularly supplements and other nutrition interventions, TCM, and NPI, are effective in improving the daily functioning of Chinese older adults with dementia. These findings contribute to our understanding of the efficacy of different intervention types for enhancing ADL in this population.

#### **Keywords**

dementia, randomized control trials, network meta analysis, interventions





# Why rehabilitation works for some but not others? Perspectives of care partners, clinicians and service providers about the implementation of the Interdisciplinary Home-bAsed Reablement Program (I-HARP)

**Prof Yun-Hee Jeon**<sup>1</sup>, Dr Luisa Krein<sup>1</sup>, Dr Mirim Shin<sup>1</sup>, Dr Johannes C Michaelian<sup>1</sup>, Prof Lee-Fay Low<sup>1</sup>, Prof Judy M Simpson<sup>1</sup>, Prof Robert T Woods<sup>2</sup>, Dr Loren Mowszowski<sup>1</sup>, Prof Sarah Hilmer<sup>1</sup>, Prof Lindy Clemson<sup>1</sup>, Prof Sharon L Naismith<sup>1</sup>, Prof Sarah Szanton<sup>3</sup>, Prof Henry Brodaty<sup>4</sup>

<sup>1</sup>The University of Sydney, Sydney, Australia. <sup>2</sup>Bangor University, Bangor, United Kingdom. <sup>3</sup>Johns Hopkins University, Baltimore, USA. <sup>4</sup>UNSW Sydney, Sydney, Australia

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Aim:** Our pragmatic RCT of the Interdisciplinary Home-bAsed Reablement Program (I-HARP) improved functional independence in people with mild but not moderate dementia, in Sydney, Australia. We aimed to examine factors/issues influencing implementation and outcomes of I-HARP.

**Methods:** I-HARP is an individually tailored 4-month rehabilitative care model, incorporated into community aged care and hospital-based community geriatric services. I-HARP involves 8-10 home visits by an occupational therapist, a registered nurse, and optional 2-4 additional allied-health supports; minor home modifications/assistive devices; and 3 individual carer support sessions. Of 116 dyads who completed the trial, 58 received I-HARP. We conducted semi-structured interviews with 28 care partners and focus groups with 12 I-HARP clinicians and 6 managers from participating services post-intervention. Qualitative content analysis was employed using NVivo12.

Results: Care partners reported substantial benefits from I-HARP, including 1) enhanced client confidence, independence in daily activities, and social engagement; 2) improved home environment safety; and 3) increased knowledge and understanding of dementia and reablement. They highlighted the value of timely and personal interactions with I-HARP clinicians, seen as well-organised, respectful, knowledgeable, compassionate, and flexible in their thinking and availability. Care partners found clients' lack of motivation/willingness to engage and worsening dementia challenging, which negatively impacted goal setting/achievement processes. Focus groups with I-HARP clinicians and managers echoed many of these aspects. Clinicians found it valuable to witness the positive impact of the care directly and learn from peers through observation (e.g., case conferences) and clinical supervision. The benefits of interdisciplinarity in their teamwork were a notable theme. Managers reported that recruiting I-HARP clinicians and eligible participants was their main challenge.

**Conclusion:** This qualitative study has provided deeper insights into the varying effectiveness of I-HARP for people with different dementia severities. Understanding of this I-HARP implementation is important in designing/improving dementia rehabilitation programs.

#### **Keywords**

Dementia, Rehabilitation, Reablement, Clinical trial, Qualitative research, Community care, Care Partners



# Dementia Awareness and Inclusivity in Multicultural Communities: Lessons Learned from an Australian Education Initiative

**Dr Diana Karamacoska**<sup>1</sup>, Ms Eman Shatnawi<sup>2</sup>, Ms Gabriela Caballero<sup>2</sup>, Mrs Emorfia Tsouros<sup>2</sup>, Dr Genevieve Z Steiner-Lim<sup>1</sup>, Ms CASS Care<sup>3</sup>, Ms Canterbury Bankstown Dementia Alliance<sup>4</sup>

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#### **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

Culturally and linguistically diverse people remain under-served and under-represented in Australian dementia research and interventions. Ongoing work in Western Sydney, Australia, has found stigma and misperceptions about dementia remain highly prevalent especially among non-English speaking communities. A multisectoral collaboration, known as the Canterbury Bankstown Dementia Alliance, was formed to address these issues. The alliance is supported by Canterbury Bankstown Council and is coled by an academic, enabling knowledge exchange and policy reform. Together with alliance members who have lived or caring experiences of dementia, we co-created a multilingual dementia education initiative involving the annual delivery of awareness raising information sessions and an exhibition to connect people with research and support services. To date, we have reached over 2,000 people from English, Arabic, Vietnamese, Cantonese, Mandarin, and Greek speaking backgrounds. The barriers that we encountered with these initiatives included: problematic translations of the word 'dementia' across the different languages; lack of culturally appropriate surveys and research tools; and low literacy levels that prevent engagement with written materials. To aid awareness raising efforts, we implemented the following enablers: refer to memory loss and Alzheimer's disease instead of dementia in advertisements; sought different avenues of funding to develop culturally appropriate educational material and surveys with community groups; employed bilingual advocates to co-facilitate information sessions with a field expert; incorporated personal stories during presentations; and embedded the alliance's activities into our professional roles to ensure commitment and continuity. This presentation will highlight strategies for effective, culturally inclusive, and accessible dementia awareness raising initiatives.

#### **Keywords**

dementia, inclusivity, diversity, multiculturalism, multicultural, communities, awareness, education





# Dementia: Understand Together – Co-creation and roll out of a inclusive community symbol as a sign of solidarity and support

Ms Aine Hutcherson, Ms Fiona Foley, Ms Roisin Guiry

HSE, Dublin, Ireland

#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

**Dementia:** Understand Together is a coalition response that aims to build understanding about dementia and create an Ireland that embraces and includes people with dementia and their families: a key priority action of the National Dementia Strategy. The campaign is led by the Health Service Executive and supported by people affected by dementia, national partners and local community champions, who are taking actions to create inclusive communities.

To visually connect action that is being taken across Ireland, representing the culture change around dementia, we developed a dementia inclusive symbol that will:

- · act as an overarching symbol of solidarity, inclusivity and support for people living with dementia
- be a sign that communities, businesses and services are working towards being dementia inclusive

The symbol was created in consultation with people with dementia, their families, national partners and local community champions, the public and the Dementia: Understand Together working group.

While the majority of people with dementia live in the community they may need understanding and support to stay active and engaged. Through the symbol we are sending a strong and visual message that people with dementia and their families are valued and respected members of our communities. It increases awareness of dementia in our communities and shows how everyone can make a difference by knowing more about dementia and displaying the symbol in all settings and spaces. The roll-out is supported by a training programme, a toolkit of resources, ongoing engagement with stakeholder and a national communications campaign.

People with dementia have said "I would be very slow to ask for help when out and about but if I saw that sign on the door I'd have no problem in asking". "I think it's going to be a game changer! It's taking things to a whole new level".

### **Keywords**

dementia, community, inclusive, awareness, connected, social, active, outcomes, society, friendly, understanding, together, symbol, solidarity, support, action, champion, partnership, accessible, Ireland







# What if the person with dementia was you? For World Alzheimer's Month 2023 Federazione Alzheimer Italia launched a dementia awareness campaign.

Mr Mario Possenti, Mrs Cristina Brioschi

Federazione Alzheimer Italia, Milano, Italy

#### **Topic**

**Dementia awareness:** Attitudes, awareness and stigma

#### **Abstract**

A social experiment was organized in a covered market in Milan: we created the conditions for market customers to experience what a person with dementia feels when they encounter difficulties in carrying out daily actions such as shopping.

The "Isola" covered market in Milan has been **Dementia Friendly since 2022**. Merchants participated in a training aimed at raising awareness. The main topics addressed were dementia, risk and prevention factors, relational aspects, with a reflection on the best ways to communicate. In particular, there was a focus on some practical elements that can make **shopping more accessible for people with dementia**. This is important to help people live with dementia and maintain their independence.

The experience allowed us to come into contact with the market's shopkeepers, together we worked to build an accessible environment in a chaotic city like Milan. In **September 2023**, we organized a social experiment, creating the conditions for market **customers to experience the sense of confusion that people with dementia often experience** in stimulus-rich environments like the market. When customers went to the butcher's counter, they were served fruits and vegetables, at the fruit stand, milk and yogurt. They were thus confronted with **incongruent and unexpected elements.** The whole thing was filmed with **hidden cameras installed for the occasion inside the market.** 

At the end of the experiment, the people secretly filmed were asked to express how they felt. We brought everything together in a short film (https://www.youtube.com/watch?v=LxVpeRaG5CA - it will be subtitled in English) which we then disseminated through our platforms (Facebook and YouTube) in order to reach as many people as possible. This awareness campaign, created to fight stigma, was seen by almost two million people in September 2023 and was relaunched by the major newspapers.

#### **Keywords**

awareness, campaign, WAM2023, Dementiainclusive, DementiaFriendly, stigma, media, video, social



# Our youth, our compass: families walking with younger-onset dementia shine light on stigma

Mrs Diana Shulla Cose, Mrs Patti LaFleur

Lorenzo's House, Chicago, USA

# **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Purpose:** For youth walking with a parent's younger-onset dementia diagnosis, our voices are the softest, yet our journey is often the hardest. We are helping to open the shades and bring light. We are telling the stories of our Mothers and our Fathers. We are the survivors who choose to advocate for a more just world for our families. Through the EmpowermentPLUS Model, we are bringing strength to stigma.

**Project Plan:** The three components of the EmpowermentPLUS Model include (1) recognize, (2) respond, and (3) empowerx2. For example, when I feel I am experiencing stigma as a daughter of my parent living with dementia—at a family party, grocery store, park or hospital, I am (A) able to recognize it, and (B) I have the tools to respond, rather than responding with fight, flight, or freeze and (C) the last piece is that my mindful and informed response empowers me as a daughter, and the PLUS symbolizes that the person who triggered the stigma is also empowered by being educated.

**Outcomes:** During our international Youth Summit, with support from Alzheimer's Society of Canada, Alzheimer's Disease International and London School of Economics, nearly 100 youth worldwide shared personal stories of when they experienced stigma as a younger family walking with dementia, and we taught the EmpowermentPLUS Model as a way to grapple and dismantle it.

**Conclusion:** We are building our alliance of empowered young ambassadors, and expect more than 200 youth at Lorenzo's Youth Summit 2024. Our Founding Executive Director, Diana Shulla Cose, and our Lighthouse Lead, Patti Lafleur, will share the youth voices and details of Lorenzo's House's strength to stigma work. We aim to share pieces of this critical work in the 2024 ADI Alzheimer's Report.

#### **Keywords**

young-onset dementia, younger-onset dementia, youth, carer, caregiver, stigma, empowerment, young people, children, kids, care partner, support, virtual, international



# Dementia Awareness and Friendliness Interventions in Asia: A Scoping Review

**Dr Siti Maisarah Mattap**<sup>1</sup>, Mr Yung Hong Lee<sup>1</sup>, Mr Dinesh Sangarran Ramachandram<sup>1,2</sup>, Miss Izzati Muhammad Khair<sup>1</sup>, Dr Jessica Watterson<sup>3,1</sup>, Prof Louise Robinson<sup>4</sup>, Dr Narelle Warren<sup>5</sup>, Dr Devi Mohan<sup>6</sup>

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# **Topic**

**Dementia awareness:** Attitudes, awareness and stigma

#### **Abstract**

**Aims:** Despite the growing number of persons living with dementia in Asia, there is a lack of comprehensive information on the current state of interventions to promote dementia awareness in these countries. This scoping review aims to map the extent of dementia education, awareness campaigns, and other interventions that promote dementia awareness and friendliness in Asia.

**Methods:** The scoping review was conducted following the Joanna Briggs Institute methodology for scoping reviews. We searched MEDLINE, EMBASE, Scopus, and PsycINFO databases to identify articles on the topic. We include awareness and friendliness interventions conducted in fifty-one Asian countries for the general population, people with dementia, or family caregivers.

**Results:** Fourteen publications were included in the review. The studies were conducted in eight Asian countries: Japan, South Korea, Indonesia, Hong Kong, Taiwan, Brazil, India, and Tanzania. The majority of the interventions available are face-to-face lectures, training, or courses on awareness and attitude towards dementia. Only two studies employed the use of technology through social media video sharing and mobile apps. A total of 11 studies reported positive outcomes, including increased knowledge of dementia, improved attitude towards people with dementia, enhanced confidence and motivation in caring for people with dementia, improved active involvement and social interaction with people with dementia, reduced stigma, and decreased dementia associated fear in older adults.

**Conclusion:** Evidence-based awareness and friendliness interventions and programmes are still lacking in Asian countries. Even so, most included studies showed positive impacts on attitudes towards dementia, social engagement among the general public and enhanced caregiving perceived values among caregivers. Efforts to increase awareness and friendliness interventions among the public through appropriate channels should be intensified in Asian countries.

#### **Keywords**

dementia awareness, friendliness, stigma, dementia attitude



# Carers' reflections on dementia awareness and friendliness in Hungary

Dr Csaba Kucsera<sup>1</sup>, Ms Anna Holpert<sup>2</sup>

<sup>1</sup>Faculty of Social Sciences, Eötvös Loránd University, Budapest, Hungary. <sup>2</sup>Independent researcher, Budapest, Hungary

# **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aims:** The analysis explores the evolution of carers' 1) dementia-awareness and dementia-related attitudes; and their 2) reflection on the perceived appropriateness of formal health- and social care services over time along their 'carer journey'.

Method: Qualitative research, thematic analysis of 22 in-depth interviews with carers.

Results: Most carers' prior knowledge about dementia was either non-existent or too vague and passive that made early diagnosis more difficult. Under such circumstances, usually an extraordinary event brought to the surface the seriousness of the situation, pressing for a medical attention. Information support accompanying medical diagnosis by doctors was often inadequate, with many carers only able to recall a few words of very simplified information, often riddled with stigma, which has not improved over the years. According to the experience of caregivers, this may have hindered coping with dementia and the complex challenges of caregiving. Over the years of caregiving, most carers became 'lay experts' on dementia through alternative sources of information and their own experiential knowledge using a trial-and-error method, and at the same time, they became ambivalent towards formal services, in particular the healthcare system. Drawing on their own example, they are advocating the increase of dementia awareness in Hungarian society, as well as the training and attitude change of professionals to make Hungary dementia friendly.

**Conclusion(s):** Hungary needs to take steps to raise general awareness of dementia, including in the formal care system, and this should be a focal point in the currently non-existent National Dementia Strategy. Carers' experience demonstrate that awareness and right attitudes are pervasive not only in early diagnosis and a more effective treatment, but also in their own coping with the complex challenge of care, and in a more meaningful and collaborative interaction between the doctor, the person diagnosed with dementia, and the carer.

# **Keywords**

awareness, stigma, carer journey, experiential knowledge, service evaluation, policymaking, Hungary



# What Does it Mean to be PALS: Coming Alongside a Memory Care Resident to Promote Dignity and Inclusion.

Ms Angie Frantz<sup>1</sup>, Ms Julie Genthe<sup>1</sup>, Mr David Troxel<sup>2,3</sup>

<sup>1</sup>Prestige Senior Living, Vancouver, USA. <sup>2</sup>Best Friends Approach, Sacramento, USA. <sup>3</sup>Consultant Prestige Senior Living, Vancouver, USA

# **Topic**

Dementia awareness: Dementia friendliness and inclusivity

#### **Abstract**

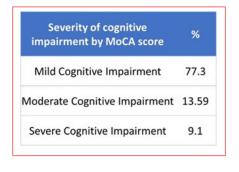
Prestige Ambassador Liaison Services (PALS) was created to provide a positive experience to residents upon moving to any Prestige Senior Living Community, by taking a proactive approach to addressing and understanding initial concerns and learning more about a resident's unique needs. A Prestige Ambassador is assigned the responsibility to partner with new residents to build a relationship with them, act as a trusted resource and provide extra attention to residents and/or their family members that may require additional focus or follow up. The goal of PALS is to ease the transition between home and our communities and ensure both our residents and their families feel comfortable and secure in their new home. In 2022 the PALS program was expanded beyond our Assisted Living residents to include residents in our Expressions Memory Care Neighborhoods, as a way to value their dignity, rights and choices in their new home.

#### Who can be a PAL?

The Executive Director or Community Relations Director selects a Department Leader (Life Enrichment Director, Maintenance Director, Dining Services Manager, Health Services Director, etc.) to be assigned as a PAL when a new resident has a move-in date scheduled. Current residents and staff members can be assistant PALs to welcome and help the new resident feel welcome at home.

#### What Does a PAL do?

- The PAL chooses a team of residents and staff who will be available as greeters on the day of move-in.
- The PAL will work with the Executive Director and Community Relations Director to make sure a "Welcome Basket" is ready.
- The PAL will follow up with the resident to ask assigned questions from the deck and assure that any concerns or needs are addressed immediately.
- The PAL will assist the resident in setting a date for their "Housewarming Party".



# **Keywords**

Dementia, Alzheimer's, Long-Term Care, Assisted Living, Advocacy, Memory Care, Communication, Dignity, Inclusion



# Using Artificial Intelligence (AI) to support clinical assessment and management of sleep disturbance for people living with dementia and mild cognitive impairment

**Prof Chris Fox**<sup>1</sup>, Dr Clare Aldus<sup>2</sup>, Dr Aidin Aryankhesal<sup>3</sup>, Ms Jess Blake<sup>3</sup>, Dr Andrea Hilton<sup>4</sup>, Dr Jayden van Horik<sup>1</sup>, Dr Anne Killett<sup>3</sup>, Ms Molly Megson<sup>4</sup>, Prof Ian Maidment<sup>5</sup>, Prof Joanne Reeve<sup>4</sup>, Dr Jinpil Um<sup>1</sup>, Dr Geoff Wong<sup>6</sup>

<sup>1</sup>University of Exeter, Exeter, United Kingdom. <sup>2</sup>Prescribing Services Ltd, Norwich, United Kingdom. <sup>3</sup>University East Anglia, Norwich, United Kingdom. <sup>4</sup>University of Hull, Hull, United Kingdom. <sup>5</sup>Aston University, Birmingham, United Kingdom. <sup>6</sup>University of Oxford, Oxford, United Kingdom

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

# **Abstract**

**Background:** Sleep disturbance for People Living With Dementia (PLWD) and Mild Cognitive Impairment (MCI) is difficult to manage in primary care, due to complex interacting personal and systemic (i.e. data integration) factors. Currently available interventions can be unhelpful or cause harm. All may provide tools for improvement.

**Aim:** To provide tailored management of sleep disturbance in primary care for PLWD/MCI and support for carers and medical professionals, via a user-friendly portal representing integrated healthcare datasets, measures of health equality, self-reported wellbeing, and clinical guidance.

**Method:** This multi-stage study comprises a realist literature review; clinical observations; focus group discussions with PLWD/MCI, carers, and clinicians; and co-design workshops.

**Results:** A novel intervention (TIMES) delivered in primary care via ECLIPSE, an NHS-validated data-processor (Prescribing Services Ltd, Buxton, Norfolk, UK). TIMES uses AI to facilitate the delivery of tailored care and improve health equity, by stratifying risk, prioritising care, and linking primary care, secondary care, prescribing, and self-reported datasets. People at lowest risk will be managed within the broader healthcare team by e.g. a healthcare assistant; people at moderate risk by a nurse (who may refer upward); and people at highest risk by a GP or a hospital specialist. We will discuss feasibility and implications of using AI to support patients, their carers, and healthcare professionals.

**Conclusion:** Al, as implemented in the TIMES intervention (https://carecoachtimes.org/), has the potential to enhance health equity, by facilitating clinical decision making to support the professional delivery of tailored care for PLWD/MCI.

# **Keywords**

Dementia, Sleep, Artificial intelligence



# Exploring older people's attitudes and preferences around the use of their routinely collected healthcare data in brain health research

**Dr Sarah Cullum**<sup>1,2</sup>, Dr Lina Groenevald<sup>1,2</sup>, Mr Cristian Gonzalez Prieto<sup>3</sup>, Dr Jasmine Appleton<sup>4</sup>, Dr Susan Yates<sup>1</sup>, Dr Daniel Wilson<sup>3</sup>, Prof Gill Dobbie<sup>3</sup>

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# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Aim:** The utilisation of routinely collected health data is rapidly increasing due to the explosion of artificial intelligence (AI), and is likely to be a cost-effective approach research tool for epidemiology and dementia prevention studies. The aim of this study is to explore older people's attitudes and preferences about sharing their routinely collected health data for research purposes, especially in the context of brain health.

**Method:** The study took place in a health district in Auckland, New Zealand, with a highly diverse population including Māori, Pacific Island, Asian and European peoples. Participants (n=28) were interviewed online using a guide that included topics around the use of de-identified health data for service improvement and health services research, sharing data with academic partners local and overseas, linkage with other health data (eg utilisation of healthcare resources, mortality data); allowing private companies to use data, and using data from people who have developed dementia or who have died.

**Results:** Participants perceived many benefits such as helping others, improving health services, advancing scientific knowledge, and giving back to the health system that had served them over their lifetime. They felt that people's pre-existing wishes about sharing health data should be heard and respected, including if they were no longer able to consent. They had concerns about sharing data with private companies, sharing inaccurate data, and the potential personal and societal consequences of sharing health data. Participants had strong opinions on how research should be conducted, including an expectation that institutions in New Zealand should collaborate to get better results, that data privacy should be maintained, and that cultural beliefs should be respected.

**Conclusion:** New Zealand consensus guidelines around the use of routinely collected health data and Al should include and reflect older peoples' wishes about the use of their data.

### **Keywords**

routinely collected health data, dementia, artificial intelligence, ethics, qualitative research





# Perspectives and roles of pharmacists in the implementation of Al and digital health interventions in medication management among people with dementia

**Mr Dinesh Sangarran Ramachandram**<sup>1,2</sup>, Ms Shobana Kumar<sup>1</sup>, Ms Sharviny Rangasamy<sup>1</sup>, Ms Rohaina Abdul Halim Gurdev<sup>1</sup>, Ms Brenda Goh Wenn Yan<sup>1</sup>, Dr Mark Cheong Wing Loong<sup>1</sup>

<sup>1</sup>School of Pharmacy, Monash University Malaysia, Subang Jaya, Malaysia. <sup>2</sup>Jeffrey Cheah School of Medicine and Health Sciences, Monash University Malaysia, Subang Jaya, Malaysia

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Background:** Artificial intelligence (AI) based interventions can optimize medication management for people with dementia. This study investigated Malaysian pharmacists' perceptions regarding the utilization of AI and digital health tools in medication management among people with dementia

**Participants and Methods:** 10 pharmacists were recruited from community and hospital settings for interviewing with consent. An exploratory qualitative study adhering to the Consolidated Criteria for Reporting Qualitative Studies was conducted. In-depth interview was conducted with the consent of all participants, and the interviews were audio-recorded for later verbatim transcription.

Results and Discussion: Six main themes were identified, namely (1) Description of Dementia care, (2) Barriers that pharmacists face in medication management for people with dementia, (3) Medication management, (4) Issues with current dementia care in Malaysia, (5) Perception of AI in medication management for people with dementia, and (6) Summary of AI in medication management for people with dementia. Theme 1 highlights the overall subpar quality of dementia care in Malaysia, whilst themes 2 and 4 reveal barriers hindering dementia care, mainly unreliable caregivers and patient denial. The involvement of carers and comprehensive instructions were vital as presented in theme 3. Theme 5 elaborates on concerns regarding practical implementation, cost-effectiveness, and usability. Our findings stress the potential of technology use in Malaysia's healthcare infrastructure. Theme 6 concludes that pharmacists are pivotal in advocating for medication adherence, especially when aided by AI and digital tools once they have demonstrated sufficient practical use.

**Conclusion:** This study establishes a foundation for future research, emphasizing patient-centered approaches and highlighting digital health's importance in dementia care for pharmacists. Collaborative efforts and further investigation are essential to advancing dementia care and effectively integrating these innovations into Malaysia's healthcare system.

# **Keywords**

Dementia, Artificial intelligence, Medication management, Pharmacists, Qualitative Study



"Co-creating a digital Alzheimer's guide - for and together with recently diagnosed patients" In this session, we would like to share the needs of recently diagnosed patients and inspire you to co-create digital tools - together with stakeholders and, most importantly, the patients.

#### Mrs Maria Cavalli

NADIO, Höganäs, Sweden

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

In the aftermath of an Alzheimer's diagnosis, patients and their families often find themselves adrift, grasping for reliable information and meaningful support. Recognizing this critical gap, our collaborative initiative in Sweden embarked on a transformative journey. Partnering closely with patients, caregivers, healthcare professionals, and researchers, we set out to co-create an innovative digital platform: the Alzheimer's Guide.

In this session we are excited to share our co-collaboration process and the specific needs of recently diagnosed patients. Through comprehensive surveys and focused group discussions, we identified pivotal patient needs:

- Clearer Diagnosis Information: Ensuring accessible and comprehensible information at the time of diagnosis.
- Support for Life After Diagnosis: Providing positive navigation tools for life post-diagnosis.
- Relationship Guidance: Equipping patients to cope with evolving relationships and challenging discussions.
- Healthcare and Workplace Rights: Informing patients about their rights in healthcare and employment settings.
- Community Connections: Facilitating meaningful connections with others experiencing Alzheimer's.

Patient insights served as the cornerstone of the content in the digital guide. The process of creating the content has involved collaborative workshops engaging over 400 participants. Launched in November 2022, the Alzheimer's Guide comprehensively addresses personal experiences, cognitive understanding, health, lifestyle, legal matters, and relationship advice. The guide's success is attributed to our partnership with patients, resulting in a user-friendly platform with distinct features. Varied information levels guarantee accessibility for all users. The platform is so much smarter thanks to our working group of patients.

We welcome you to join us to learn more about the needs and the collaborative process! Listen to what the representatives from our patient working group say about being part of creating supportive resources for individuals affected by Alzheimer's disease!

#### **Keywords**

innovation, digital support, patient information, eHealth, co-creation,



# Dementia Ideal Care Map: Ecosystem view of best practices and new care pathways enabled by technology and community

Dr Wen Dombrowski<sup>1</sup>, Ms Mikele Bunce Epperly<sup>2</sup>

<sup>1</sup>CATALAIZE, Pasadena, USA. <sup>2</sup>F. Hoffmann-La Roche Ltd, Basel, Switzerland

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Aims:** Much work has been done by nonprofits, industry, and academics globally to identify best practices for the care of people living with dementia (PLWD). However, these best practices are located in disparate repositories of information and tend to focus on one phase of the patient journey (such as diagnosis) or focus on one relevant group (such as just physicians or just policymakers).

We aimed to fill this gap by developing an innovative **Dementia Ideal Care Map** that everyone in the dementia **ecosystem** can use as an **actionable tool** to impact public awareness, policies, funding, research, training, services, and technology design. Intended audience includes policymakers, academic and industry researchers, technology developers, health system leaders, clinicians, social services workers, patient advocates, PLWD, families, and communities at large.

**Method & Results:** Dementia Ideal Care Map summarizes in one comprehensive diagram global best practices for:

- Dementia Awareness and Risk Reduction (including public health campaigns, dementia friendliness, inclusive technology/service/research design);
- Dementia Diagnosis Care Pathways (with the help of community partners, biomarkers, digital cognitive assessments, telehealth/virtual brain health clinics);
- Support for Carers and PLWD (before/during diagnosis, immediately post-diagnosis, and ongoing years);
- Non-Pharmacological Interventions (music/dance/art therapies, psychosocial interventions, training informal carers);
- Medical Care (assessments, medication treatments, other levels of care).
- Furthermore, it visualizes the infrastructure needed to enable the above best practices:
- Dementia as a Public Priority (policy, funding, labour laws, healthcare system readiness, collaborations);
- Technology Innovations (*nearly 100 technologies* complementing each best practice, including digital health, AI, and information systems for data sharing);
- Research (new approaches, engaging PLWD and carers in co-design, inclusion of underrepresented and MCI);
- Education and Training (for clinical professionals and care workers, emphasizing PLWD's personal preferences and cultural context).

**Conclusion:** Dementia Ideal Care Map is a practical tool for planning and coordinating dementia care.

# **Keywords**

dementia, innovation, technology, digital health, policy, awareness, prevention, screening, diagnosis, treatment, monitoring, research, training, workforce, care partners, caregivers, community, health



# Designing for dementia: empathetic innovation in a socio-technical system.

Dr James Brown, Dr Matthew Ash, Dr Sebastian Moyano

Supersense Technologies Ltd., Cambridge, United Kingdom

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

Providing effective and compassionate support for people with dementia necessitates a nuanced, multidimensional approach that takes into account not only social, emotional, ethical, technical, and systemic complexities but also recognises the individuality of each person's experience, abilities, and symptoms. While wearables, video surveillance, and ambient sensors promise a revolution in assistive technologies, their practical adoption is stymied by issues ranging from privacy concerns to a lack of user-friendly interfaces. We champion a socio-technical systems approach to tackle these issues through empathetic innovation, a method that deeply involves stakeholders—those living with dementia, carers, healthcare professionals, and commissioning bodies—at every stage of product development.

Funded by the Alzheimer's Society and working with local carer organisations and Essex County Council, we have identified specific challenges with the technologies currently in the market. These issues include privacy concerns associated with intrusive video surveillance and the necessity for users to be tech-savvy, which poses a challenge for people new to the internet, smartphones, or apps.

Ambient sensors have emerged as a viable solution to many concerns, providing a discreet method of monitoring that can integrate seamlessly into an individual's daily life. These sensors offer behavioural insights coupled with contextual information about daily activities, and can track the progression of physical and cognitive decline over time. However, their potential can only be fully realised through empathetic innovation that involves holistic engagement across the health and social care ecosystem.

Our presentation will share insights and case studies from our empathetic approach and our work to ensure that technology not only integrates seamlessly into daily life but also offers actionable information for healthcare providers. This work represents a pivotal first step towards realising effective preventative care within domestic settings, elevating both the dignity and quality of life for those living with dementia and their carers.

#### **Keywords**

dementia, innovation, co-production, ambient sensing, carers





# Development and implementation of the person-centered Minnity app for professional caregivers, adapted to the Montessori method for persons with dementia

Dr Katarzyna Hess-Wiktor Minnity, Stockholm, Sweden

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

As person-centered care approaches become golden standard, a need for effective facilitation tools increases. In this context, the Minnity app has emerged as an innovation in the field of home care.

Minnity is a response to the evolving needs of elderly individuals, especially those with cognitive impairment. It offers personal care workers easy access to information on the care recipients' needs and preferences, a space for effective communication with team members and informal caregivers as well as digital training in microlearning format.

Minnity is developed in extensive co-creation processes, involving caregivers, care recipients and subject matter experts. User feedback played a pivotal role in shaping the app's features and functionality, ensuring that it addresses the real-life care challenges. Since 2018, the app has been used by over 900 care professionals providing care to over 700 elderly individuals, many of them with cognitive impairment. Minnity is used in Sweden, France and Belgium.

The presentation will show the development and implementation of Minnity in France, where collaboration with Montessori Lifestyle / AG&D allowed to support professional caregivers to understand who the care recipient is as a person, thus empowering them in the caregiving relationship. We will show how an innovative digital tool can integrate Montessori principles, promoting control, engagement, and a sense of community for individuals receiving care. Also, how Minnity helps to adapt the environment and build on the individual's strengths, making the caregiver an enabler for the care recipient.

Minnity represents a pioneering approach to home care, bridging the gap between technology and person-centered care. By seamlessly integrating Montessori principles and user-driven design, Minnity offers a promising solution to enhance the quality of life for individuals with dementia while supporting their caregivers. This presentation will explore Minnity's development journey, its impact on care, and potential for broader applications.

# **Keywords**

innovation, digital tools, professional caregivers, Montessori, person-cenetred care



# Usability and co-design for a person-centered rehabilitation approach: the Alzheimer's and dementia ministerial fund (2021-2023) in Veneto Region, Italy

Dr Marco Simoni<sup>1</sup>, **Dr Cristina Basso**<sup>1</sup>, Dr Donata Gollin<sup>2</sup>, Dr Silvia Netti Tiozzo<sup>1</sup>, Dr Alessandra Zapparoli<sup>3</sup>, Dr Carlo Gabelli<sup>2</sup>, Dr Pierangelo Spano<sup>3</sup>

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# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Aims:** Neurocognitive Disorder, due to its complex, chronic, and progressive nature, represents a public health priority and challenge. Currently, access to non-pharmacological and rehabilitation treatments for people living with dementia is hindered by cultural, social, and economic barriers. In order to overcome these obstacles, as part of the Three-Year Activity Plan financed by the Alzheimer's and dementia ministerial fund, the Veneto Region has promoted the implementation, experimentation, evaluation, and diffusion of telerehabilitation within 11 clinical centers, proposing a study on the usability and co-design of innovative paths, spreading a person-centered rehabilitation culture.

**Methods:** The study involved 220 participants with mild-to-moderate neurocognitive disorder and 220 care-partners, facing the following phases:

- selection of participants;
- two training sessions on the use of the tool;
- 8-week telerehabilitation process, in asynchronous mode;
- implementation of Usability-Working-Groups with the involvement of 80 people living with dementia for the co-design of solutions and improvements of the software;
- data collection and analysis.

**Results:** The project collected indirect and direct data relating to the usability of the software, allowing a revision of the tool to promote greater adherence. Specifically, indirect usability data collected were the following:

- degree of adherence to the program (Task Completion Rate);
- execution speed over the 8 weeks (Task Completion Time);
- degree of usability through the System Usability Scale;
- levels of satisfaction (qualitative questionnaire);
   Direct usability data were collected by the Usability-Working-Groups through participant observation and discussion. Results are currently being analyzed.

**Conclusions:** The involvement of the person living with dementia in the design of innovative treatment paths represents an important step to:

- promote the elimination of the stigma, giving the person the opportunity to express their point of view;
- implement services that take into account the preferences, needs, and characteristics of the person;
- promote access and reduce the rate of abandonment of rehabilitation treatments.

# **Keywords**



# The level of burden of life, depression, anxiety, and well-being among caregivers of elderly with and without dementia

#### **Dr Fahad Manea**

Kuwait University - Faculty of Allied Health Sciences Health, Kuwait City, Kuwait

# **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Aims:** This study aimed to compare level of burden of life, depression, anxiety, and well-being among caregivers of elderly with and without dementia living in Kuwait.

**Methods:** Cross-sectional study was conducted. Demographic data were collected. Self-administered questionnaires: ZBI-12, HADS, and WHO-5 were used. Independent t-test was used to determine the differences between the caregivers.

**Results:** The study included 260 participants, 162 caregivers of elderly with dementia; 98 caregivers of elderly without dementia. The independent t-test showed significant differences between the level of burden between the caregivers of elderly people with and without dementia (p<.05). The caregivers of elderly people with dementia have a greater burden (mean = 18.27) than caregivers of elderly people without dementia (mean= 14.44). The independent t-test showed significant differences of anxiety between the caregivers of elderly people with and without dementia (p=.002). The caregivers of elderly people with dementia have a greater anxiety (mean= 10.49) than caregivers of elderly people without dementia (mean= 8.61). The independent t-test showed significant differences between the level of well-being between the caregivers of elderly people with and without dementia (p=.013). The caregivers of elderly people with dementia have a lower quality of life (mean = 51.28) than caregivers of elderly people without dementia (mean= 58.90)

**Conclusion:** Most caregivers of the elderly with dementia were anxious, experienced mild to moderate burden, low quality of life, and had borderline depression. Health care professionals should consider these issues facing caregivers when providing services for their elder people with dementia.

# **Keywords**

caregivers, quality of life, older adults, burnout, dementia



# ALZ\_AWARE: Dementia awareness in remote communities across the country

#### Ms Fusun Kocaman

Turkish Alzheimer Association, Istanbul, Turkey

# **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

The ALZ\_AWARE project is dedicated to enhancing dementia awareness and support in remote communities across the country. This initiative involves organizing 2-day face-to-face training sessions in 5 cities selected based on their remoteness from the association's headquarters.

#### The training program comprises four comprehensive modules:

Module 1 Understanding Dementia, provides a fundamental understanding of dementia, emphasizing caregiving skills and effective communication strategies. Participants gain insights into the challenges faced by PwD and their caregivers, equipping them with essential knowledge to provide better care.

Module 2 Group Psychotherapy and Psychodrama, introduces group psychotherapy and psychodrama techniques fostering a supportive environment. Attendees learn to address the emotional and psychological needs of PwD and their families, promoting holistic well-being.

Module 3 Social and Legal Rights educates participants on the social and legal rights of PwD and their caregivers recognizing the importance of advocacy and support. Empowering them with knowledge of available resources and legal protections to improve QoL for those affected.

Module 4 Dementia Champion Training aims to train volunteers to become dementia champions for their communities. They receive specialized training and guidance to raise awareness within their regions, creating a supportive network.

The project seeks to bridge the knowledge gap and promote dementia care in remote communities, by dispatching experts from the HQ to train them as specifically tailored to the needs of these areas.

The initiative aims to create a stronger support system for families by building a network of informed and compassionate individuals who can make a positive impact on the lives of PwD and their families. Anticipating the positive impact of these training sessions, the ALZ\_AWARE project envisions the formation of local branches in remote communities which would serve as hubs of knowledge and support, further strengthening the network of care and advocacy for PwD and their families.

### **Keywords**

awareness, remote communities, training, caregivers, effective communication, group psychotherapy, psychodrama, social and legal rights, advocacy, Dementia Champion Training, knowledge hub,



'It was an education, a life education'; exploring how online learning supports family carers of people living with dementia: A case study from Ireland.

# **Dr Fergus J Timmons**

The Alzheimer Society of Ireland, Dublin, Ireland

# **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** Family carers play an important role in looking after people living with dementia. Yet they are often unprepared for this challenge. The Alzheimer Society of Ireland (ASI) has been delivering online education and training for family carers of people living with dementia since 2016. Previous research has shown that online education and training can help reduce stress, isolation, and carer burden. However, it is not always clear exactly how education and training lead to these reductions.

**Methods:** This paper will report the findings of a doctoral research study which investigated if and how one such online education and training course provided by ASI supports family carers of people living with dementia. This research employed a case study methodology and obtained both qualitative and quantitative data from cohorts of learners who participated in the course between 2019 and 2021.

**Findings:** Participation in the online training course supported family carers of people living with dementia in several ways. The vast majority of course participants benefited from informational and educational support that allowed them to develop a range of practical skills which helped them in their care role. Course participants also gained support through interactions with course materials, expert tutor advice and via meaningful dialogue with other family carers of people living with dementia. Consequently, most course participants expressed positive feelings of satisfaction about the course saying it empowered them, reduced their stress levels, and increased their confidence in their ability to provide care to their family member living with dementia.

**Conclusion:** This paper gives a detailed insight into how family carers of people with dementia gained support from participating in an online education course. The paper should be of interest to educators, policy makers, Non-Government Organisations and any other provider aiming to support family carers of people living with dementia.

# **Keywords**

family carers, dementia family carers, online education and training, case study, carer supports, peer learning, tutor presence.



# **Enhancing Home Care through a Multicomponent and Integrated Model: A Proposal**

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# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

# **Abstract**

Long-term care and home support for individuals living with dementia are among the primary challenges in today's healthcare and welfare system. Modelling interventions that address the person's multidimensionality and make home care functional and compatible with other forms of support is crucial. Interventions should be personalized and aimed at considering the person as a whole, overcoming fragmentation, and territorial/methodological heterogeneity. The objective of this abstract is to present a multi-component model as a potentially more effective and efficient response to home care. Dementia impacts individuals' quality of life, imposing a significant impact on care partners, who must navigate complex care scenarios, including executing multiple therapies and managing comorbidities. This requires competence, experience, and expert guidance (often limited). According to the literature the Care Management and Coordination model is capable in sustaining individuals living with dementia, alleviating the effects of care partners, and helping them in providing effective care and assistance. This model expands upon the Care Ecosystem Model, introducing personalized Care Navigation Programs within the domain of Long Term Care. Case Navigators provide caregivers with counselling, training, and customized care plans. The model emphasizes tertiary prevention for individuals living with dementia and primary and secondary prevention for caregivers. In the model Case Navigators facilitate continuous and structured communication between caregivers and the local/virtual networks. Direct coordination with the proximity network is a pivotal feature of the model, to help carers access care support. Continuous evaluation and monitoring of individuals' quality of life underpin the model, ensuring the provision of tailored support. The proposed model places paramount importance on preserving the multidimensional quality of life for individuals. By offering personalized interventions, it would be possible to foster care partners' skills, and ultimately improve the overall quality of life through continuous support and network integration.

#### **Keywords**

Quality of life, Long Term Care, Care Navigation





# Hard to reach and hidden: improving identification of young dementia carers

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# **Topic**

Support for dementia carers: Young carers

#### **Abstract**

**Aims:** Young dementia carers (YDCs) rarely receive appropriate training and support. Their visibility and identification is dangerously low, in part due to low level of self-recognition and a lack of awareness amongst relevant support services and professionals about this cohort and their needs. As a consequence, support initiatives being developed are failing to reach them. In this study we aim to explore the success (or failure) of YDCs identification pathways, as well as the barriers and enablers to their implementation.

**Method:** An explorative qualitative approach was followed, drawing on the experiences of parents of YDCs, dementia researchers, professionals in the field of dementia/young carers, and young adult carers. Data collection involved semi-structured interviews (n=17) and a participatory workshop to discuss and critique themes that emerged from interview data, and to explore strategies to increase the visibility and identification of YDCs.

**Results:** Five themes were identified: A 'whole family approach' (as a pathway to identification); 'Not a carer' (self/family identification); A postcode lottery (high variability of support services); Tailored support that is 'fit for purpose'; and The 'power' of peer support. Recommendations and actions to help increase the visibility and identification success of YDCs are also proposed.

**Conclusion:** Our findings support the need for a broad and holistic approach to the identification of YDCs that runs alongside the development of support initiatives that are accessible and relatable. The support itself will play a role in improving subsequent identification, or it could hinder it if not 'fit for purpose'.

#### **Keywords**

Young person, Young carer, Adolescents, Younger Onset Dementia, Dementia, Carer, Schools



# Health and social care professionals' experiences of supporting children and young adults with a parent diagnosed with dementia

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# **Topic**

Support for dementia carers: Young carers

#### **Abstract**

**Aim:** The aim of the study was to describe health and social care professionals' experiences of identifying children and young adults with a parent with dementia and meeting their support needs.

**Method:** Thirteen health and social care professionals, predominantly registered nurses, and social care workers, who supported people living with dementia and their families were recruited by snowball sampling. They were employed as dementia nurses, family caregiver advisers, and hospital social workers. Semi-structured interviews about their experiences of supporting children and young adults with a parent with dementia were conducted via video calls. The interview data was analysed with qualitative inductive content analysis.

**Results:** The health and social care professionals described children and young adults with a parent living with dementia as a forgotten group. Participants were employed to support people living with dementia and adult care partners and highlighted a lack of available services with the ability to support children and young people with a parent with dementia. In the absence of appropriate support services to refer to, they struggled to provide support themselves to the best of their knowledge and resources. It was important to be flexible and adapt the support to the age and the situation of the child/young adult. Because of the stigma associated with dementia, creating a safe environment was crucial to promote trust and openness in the communication about the children's/young adult's challenges and support needs.

**Conclusion:** Children and young adults with a parent living with dementia are easily overlooked by health and social care services. There is a need to develop guidelines and services directed to children and young adults living with a person with dementia. Further, the general awareness and knowledge about young onset dementia and its impact on families requires further attention.

### **Keywords**

Caregiver, children, cognitive impairment, dementia, nursing, social work, young adults



# A basic tool for transdisciplinary collaboration: the EPND Glossary

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# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

**Background:** Innovation requires effective communication enabling transdisciplinary collaboration. Transdisciplinary glossaries are lacking in the field of neurodegenerative disorders; we developed one for the European Platform for Neurodegenerative Diseases (EPND, www.epnd.org), which aims to make neurodegeneration research data and samples findable, accessible, interoperable, and reusable (FAIR).

**Methods**. We used open-source tools to create a Glossary with Wiki-based editing and sharing principles. We identified relevant modules, drafted a starting list of terms and asked the specific experts to complete the modules. The experts edited and integrated definitions and references and provided additional terms. A short tutorial gave user guidance for the platform. This initial draft has been reviewed by EPND members. A questionnaire is collecting feedback on utility and possible improvements for use within and outside EPND. We are recording metrics of access and contribution.

**Results.** Currently, the Glossary includes 524 entries across eight Modules: Acronyms, Hub Framework, Data Terms, Legal, Regulatory, Biomarker, Business, and Clinical (https://bit.ly/EPND-glossary). Terms are mostly discipline-specific; specific EPND usage (e.g., avoiding the use of "metadata", or "syndication") occurs mostly in the "Hub Framework" and "Data Terms" modules. We enable viewing CC-BY access, and the use of our GitHub repository instructions to build analogous platforms (https://github.com/MaastrichtU-CDS/EPND-Glossary).

**Discussion**. Based on transdisciplinary collaboration and wiki-like verification standards, the EPND Glossary will facilitate interactions between industry, academia and other stakeholders within EPND and can be used or adapted to other initiatives. The ongoing evaluation of its efficacy will allow to derive metrics to evaluate transdisciplinary collaboration.

### **Keywords**

transdisciplinary collaboration, biomarker, neuroscience



# Experts by experience – user involvement in assessment of research proposals

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Norwegian Health Association, Oslo, Norway

# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

**Introduction:** The Norwegian Health Association is the national patient organization for persons with dementia and their supporting carers. Since 2001, the organization has allocated over 20 mill euros to projects through the Dementia Research Programme.

Here we describe our work with user involvement in assessment of research proposals.

**Aim:** Lay persons with lived dementia experience can be a resource related to research proposals assessment, offering unique insights that researchers cannot get elsewhere. This approach can be useful to other institutions and countries.

**Approach:** We have established a User Representative Panel (URP) consisting of four to six next of kin with lived dementia experience, recruited amongst the organization's volunteers. Based on their personal experience with dementia, the panel members grade lay summaries of proposals according to three criteria: 1. Potential impact 2. User involvement; 3. Language. The URP's recommendations are presented to our international scientific grant committee. In cases where the scientific quality of two or more proposals is found equal, the URP's assessments guide the recommendations for funding.

To implement this method, the members of the URP need training in assessing proposals and education on user involvement in research. We also find it crucial to help them build confidence in being experts by experience.

**Results:** Implementing user involvement in the grant decision process gives the users direct impact. As the applicants present their project in lay language, the common understanding of dementia research increases. This might impact the transition of the outcomes into clinical practice as well as health system policies, and serve a societal purpose.

# **Keywords**

User involvement, funding, proposal assessment, research grant





# **Advancing Biobanking in Europe**

#### Prof Jens K. Habermann

BBMRI-ERIC, Graz, Austria

# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

BBMRI-ERIC is the largest European research infrastructure for biobanking that currently includes 24 countries and one international organization. BBMRI-ERIC's mission is to establish, operate and develop a pan-European distributed research infrastructure of biobanks and biomolecular resources to facilitate the access to resources and facilities and to support high-quality biomolecular and medical research. BBMRI-ERIC brings together all the main players from the biobanking field – researchers, biobankers, industry, and patients – to boost biomedical research. To that end, BBMRI-ERIC offers quality management services, support with ethical, legal, and societal issues, and several online tools and software solutions. One of these tools is the BBMRI-ERIC Directory that collects and makes available information about biobanks, samples, and associated data to researchers in the biomedical field. It encompasses more than 400 biobanks hosting over 100 million samples.

BBMRI-ERIC is engaged in more than 23 active EU projects which includes projects in different areas of research, including, neurological disorders, personalised medicine, oncology and health data.

On dementia, the discovery tools of BBMRI-ERIC, namely BBMRI Directory and BBMRI Federated Platform, allows researchers to search for collections in this research field, across more than 400 organisations. Currently, in the BBMRI Directory there are 13 organisations across Europe that host samples and/or data on dementia.

In terms of digitalization and tools solutions, BBMRI-ERIC continues to strengthen its portfolio by (i) the initiated federated search and analysis platform for sample-level and patient-/donor level data, (ii) data quality and certification, (iii) expedited access procedures for samples & data, (iv) data pooling, and (v) big data analysis.

### **Keywords**

biobanking, biomedical research, biomolecular



# Machine learning to predict dementia for American Indian and Alaska Native Peoples

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<sup>1</sup>University of California Irvine, Irvine, USA. <sup>2</sup>University of Colorado Anschutz Medical Campus, Aurora, USA

# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Aims:** Identifying individuals at high risk of dementia is critical for early diagnosis and intervention. To date, few dementia risk prediction models have been developed using electronic health record (EHR) data and none have been developed for American Indian and Alaska Native people (Al/ANs). This investigation aimed to develop a risk prediction model for all-cause dementia and compare the performance of two machine learning algorithms with traditional Logistic Regression (LR).

Methods: EHR data from the Indian Health Service (IHS) National Data Warehouse and related databases were extracted. This study includes 17,451 Al/AN adults aged 65+ years old who did not have a dementia diagnosis during the baseline period (fiscal year [FY] 2007-2011). Three algorithms were analyzed to predict the risk of all-cause dementia diagnosed between FY 2012-2013: LR, Least Absolute Shrinkage and Selection Operator Regression (LASSO), and eXtreme Gradient Boosting (XGBoost). Model performance was compared using area under the receiver operating charactering curve (AUC) while data pre-processing efforts were also described and compared.

**Results:** During FY2012-2013, 631(3.6%) adults were diagnosed with incident dementia. As shown in Figure 1, the three algorithms exhibited similar discriminatory performance (AUC: 0.826, 0.826, 0.822). Important

model Auc

Age Only 0.740

LASSO 0.826

LR 0.826

XGBoost 0.822

Figure 1. Receiver operating characteristic (ROC) curves for age only, LR, LASSO, and XGBoost prediction models for 2-year incident, all-cause dementia.

Abbreviations: LR=Logintic Regression, LASSO=Least Absolute Shrinkage and Selection Operator, XGBoost=Extreme

predictors identified by the 3 algorithms had substantial overlap: all shared 10 common predictors among the top 15 identified by each algorithm. Compared to LR and LASSO, XGBoost required significantly less investigator-driven data pre-processing and can automatically examine predictor interactions as well as non-linear relationships.

**Conclusions:** Routinely collected EHR data can be used to predict dementia risk among Al/AN older adults. The developed risk prediction model could serve as a clinical tool to aid in identifying Al/AN individuals at high risk for dementia, which is particularly important given the limited resources for dementia training and screening among IHS and Tribal clinicians.

### **Keywords**

Alzheimer's Disease and Related Dementia (ADRD); Artificial Intelligence; Electronic Health Record Data; Indigenous Populations; LASSO; Risk Prediction; XGBoost.



# Variations in the ApoE gene and the clinical, biochemical, and socio-demographic profiles of individuals with Alzheimer's disease residing in both the northern and southern regions of Kazakhstan

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# **Topic**

Dementia research and innovation: Epidemiology

# **Abstract**

**Background:** Alzheimer's disease (AD) is the most frequent cause of dementia in seniors and is also one of the critical social issues of modern healthcare. Since AD is considered a multifactorial condition, the significance of particular risk factors in different ethnic populations is constantly reevaluated.

**Objective:** Our study has compared clinical data, blood biochemical parameters, various socio-demographic characteristics, and ApoE gene polymorphism in people diagnosed with Alzheimer's dementia from Kazakhstan's north (Astana city) and south (Almaty city) regions.

**Methods.** The study group consisted of 181 individuals with AD; the control group included 244 healthy seniors comparable in sex and age to the dementia group.

**Results:** In our cohort, smoking, clinically significant depression, dyslipidemia, impaired glucose metabolism, insulin resistance, and liver dysfunction were significant dementia-associated variables. In particular, higher levels of HDL, lower ALT, and a higher total bilirubin and AST/ALT ratio were discovered. Following the literature, the most important risk factor for the development of AD is the genetic possession of the ApoE 4 gene. In our cohort, the ApoE4 genotype was more frequent in the AD group compared to the control and was more common among AD patients from the northern region. In addition, the participants from Astana city had a high incidence of strokes compared to the cohorts from Almaty city, most likely due to the region's high LDL levels. However, a high prevalence of clinically severe depression was found in the southern area.

**Conclusion:** Our results further emphasize the importance of considering bio-geographic and environmental elements when studying AD. These findings may be helpful for further study and the development of personalized approaches toward managing and treating Alzheimer's disease in different regions.

#### **Keywords**

Alzheimer's disease, dementia, cognitive impairment, blood biochemical parameters, ApoE gene polymorphism, comorbid diseases



# Associations of cognitive impairment, functionality and depression with the risk of all-cause and cardiovascular event mortality: a longitudinal study in the Chilean population 60 years and older

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# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Aims:** Study the relationship between suspected cognitive impairment (SCI), functionality and suspected depression (SD) with the risk of all-cause and cardiovascular event mortality in the Chilean population aged ≥60 years.

**Method:** Prospective cohort study based on the Chilean National Health Survey 2009-2010, a nationally representative prevalence study. Follow-up data on mortality were available until 2020. We included n=1,227 participants aged ≥60 years. A case of SCI was defined as a score <13 in the abbreviated Mini-Mental State Examination (score from 1-19). Lower functionality was defined as a score >6 in the Pfeffer test (score from 0-33). SD was defined as the presence of ≥5 depressive symptoms during the last year, assessed with the CIDI-SF scale.

The associations of SCI, lower functionality, and SD (independent variables) with all-cause and cardiovascular mortality (dependent variables) were investigated using Cox proportional hazard models. The models adjusted for self-reported sociodemographic and lifestyle variables. Results were expressed as Hazard Ratios and 95%CI (HR; 95%CI).

**Results:** Participants were on average 71.7 years old and 60.3% were women. During the follow-up, 431 individuals died from all-cause and 107 from a cardiovascular event. SCI was associated with higher risk of all-cause and cardiovascular mortality by 60% (HR:1.60; 95%CI 1.25-2.05) and 107% (2.07; 1.28-3.34), respectively. Lower functionality and SD were associated with higher all-cause mortality risk by 89% (1.89; 1.19-3.01) and 69% (1.69; 1.25-2.28), respectively. No significant associations were observed for functionality and SD with cardiovascular mortality.

**Conclusion:** Chilean participants ≥60 years with SCI, lower functionality or SD have a higher risk of premature mortality, as compared to those without these conditions. Policies to preserve mental and cognitive health in this age group are warranted to promote a healthy aging.

#### **Keywords**

Mental health, Mortality, Cognitive impairment

Exposure	All-cause mortality			CVD mortality			
	HR	95% CI	p-value	HR	95% CI	p-value	N
Suspected cognitive impairment	1.60	1.25-2.05	1.8e-04	2.07	1.28-3.34	0.003	1227
Lower functionality	1.89	1.19-3.01	0.007	1.75	0.73-4.19	0.211	146
Suspected depression	1.69	1.25-2.28	6.6e-04	1.14	0.58-2.24	0.700	1094



# Early Detection Memory Screening with Older Adults in Armenia

Dr Jane Mahakian, Dr Sona Mkhitaryan

Alzheimer's Care Armenia, Yerevan, Armenia

# **Topic**

**Dementia risk reduction:** Public health campaigning

#### **Abstract**

Researchers investigated the prevalence of cognitive impairment utilizing a mobile early detection memory screening test to assess 4000 people in Armenia. This is the first time a study examining the prevalence of dementia country wide in Armenia has been conducted. Utilizing a mobile van, the team followed the Armenian EyeCare Project's mobile hospital throughout Armenia and performed early detection memory screening with the Montreal Cognitive Assessment test (MoCA). The team also trained 650 primary care physicians and nurses on early detection as well as on Alzheimer's disease.

**Method:** The Brain Health Armenia Project's mobile clinic administered the Montreal Cognitive Assessment test and a self-report healtcare survey in collaboration with the Armenian EyeCare Project in every region of Armenia through a mobile clinic outfitted with a multidisciplinary healthcare team which screened people in polyclincs, hospitals and doctor offices.

**Results:** In June 2022, The Brain Health Armenia Project, Phase 1 was launched. It is the first mobile early detection memory screening and Alzheimer's disease training program in Armenia. The mobile screening team has screened 4,388 individuals between the ages of 40-93 in 39 villages and towns throughout Armenia. Of those screened, 35.7% have shown some degree of cognitive impairment.

**Discussion:** The Brain Health Armenia Project has become a pipeline to identify people at high risk for cognitive impairment. The project is an innovative approach to addressing the need for comprehensive early detection cognitive screening as well as the overall healthcare of the person with dementia in Armenia.

# **Keywords**

early detection, risk factors, dementia, healthsystem preparedness, early intervention, public health, alzheimers. brain health, memory screening, armenia,



# An inclusive and participatory approach for dementia risk reduction: Netherlands Dementia Prevention Initiative (NDPI)

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# **Topic**

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** A proportion of dementia cases is likely attributable to modifiable risk factors, with risks being distributed unequally in the population. While people with low socio-economic status or migration

**Background:** have higher risk, they are underrepresented in research and prevention programs. The Netherlands Dementia Prevention Initiative (NDPI) is a national consortium, funded as part of the National Dementia Plan, investigating if and how we can reduce dementia risk with special attention to vulnerable groups.

**Methods:** NDPI consists of five projects. ENGAGE uses a mixed-methods approach of interviews, focus groups and survey research of the target group, and quantitative evaluation of six completed prevention campaigns to itentify mechanisms of effect and failure in reaching the population. COMMUNICATE explores the wants, needs and barriers of for communicating about dementia risk in order to tailor best-practice and ethically sound risk communication approaches through interviews, focus groups and surveys. INFORM and INTERVENE develop and conduct public health and individual-focused interventions in co-creation with the target group including participatory action research at neighborhood level and assess their effectiveness in a randomized trial. IMPACT assesses knowledge about dementia risk reduction in current and future health professionals and develops (online) teaching modules. Junior researchers participate in the NDPI Junior Researchers Training Program to stimulate personal development and improve methodological and implementation/dissemination skills.

**Results:** NDPI aims to deliver 1) insights in how to reach, engage and communicate with a diverse population; 2) insight in the facilitators and barriers for large-scale implementation of dementia prevention; 3) knowledge whether population-based and individually-tailored interventions are effective for increasing awareness and improving dementia risk profiles; and to 4) provide an infrastructure for long-term follow-up with assessment of clinical outcomes: cognition, functioning and dementia.

**Conclusion:** Results will inform future real-world, inclusive dementia risk reduction approaches at the population- and individual-level.

### **Keywords**

Brain health, Dementia, Ethics, Health inequities, Interventions, Prevention, Public health, Risk communication, Risk reduction



# The Brain Health Scotland Guidelines for Clinical Practice in Brain Health Clinics

**Dr Catherine Margaret Pennington**<sup>1,2</sup>, Ms Anna Borthwick<sup>1</sup>, Mr Neil Fullerton<sup>1</sup>, Prof Elaine Hunter<sup>1</sup>, Mr Hugh Masters<sup>1</sup>, Ms Helen Skinner<sup>1</sup>, Dr Jenny Waymont<sup>2</sup>

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# **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

Brain Health Scotland is a joint endeavour of Alzheimer Scotland and the Scotlish Government established in 2020. Our aim is to promote lifelong brain health and dementia prevention. A key part of this is the establishment of brain health clinics within NHS Scotland, the first of which is due to open in Aberdeen in late 2023. Brain Health Scotland has recently published Guidelines for Clinical Practice in Brain Health Clinics. These are have been developed in close collaboration with old age psychiatry, neurology, public health, radiology and allied health professionals. The Guidelines detail how a Brain Health Clinic can work with the general public to provide personalised brain health risk factor profiles and practical, pragmatic advice and support with risk factor modification. We propose a pathway where members of public can self-refer to the Brain Health Clinic, or be referred by healthcare professionals in primary care, public health and other relevant disciplines. Individuals undergo initial assessment by a specialist practitioner (nurse or allied healthcare professional), followed by discussion with a consultant specialising in cognitive disorders. Depending on individual risk profile and cognitive status, they may be supported with self-led risk factor modification, followed-up in the specialist practitioner clinic, or reviewed in person by the consultant. Individuals may be referred for neuropsychological, radiological or systemic investigations as clinically indicated. The Brain Health Clinic will liase closely with services such as substance misuse and diabetes clinics, alongside local dementia diagnostic services, allowing onward referral to specialist services if needed. We aim for the Guidelines for Clinical Practice to be practical and pragmatic, and whilst adjustments may be needed to tailor services to specific population needs, we hope that the Guidelines will be of broad applicability and utility for clinicians developing brain health services.

#### **Keywords**

Brain health, dementia prevention, clinical guidelines, brain health clinic



# Clinical profile and serum Vitamin D level among dementia patients: An Insight from Ethiopia

#### Dr Yared Zenebe Zewdde

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# **Topic**

Dementia risk reduction: Dementia and nutrition

#### **Abstract**

**Background: & aims:** Vitamin D deficiency is linked with the risk of developing dementia and Alzheimer disease. There is paucity of data on serum vitamin D level among patients from tropical countries such as Ethiopia. The objective of this study is to determine the prevalence of vitamin D deficiency and associated factors among dementia and Alzheimer disease patients in Ethiopia.

**Method:** An institution-based cross-sectional study was conducted among adult patients presented with cognitive complaints and diagnosed with Alzheimer's disease and Alzheimer's disease related dementia who visited the Lancet General Hospital in Addis Ababa, Ethiopia from November 1 – August 30, 2023. Sociodemographic and clinical data were obtained at presentation with serum vitamin D level determined subsequently. Cognitive test was assessed using the Montreal Cognitive Assessment-Basic (MOCA-B). Descriptive and inferential statistical analysis were done and measures of estimated crude and adjusted odds ratio with95% CI were constructed and a p value <0.05 was considered statistically significant.

**Results:** A total of 60 adult patients with dementia were enrolled. The mean (SD) age of dementia patients was 69.4 (1.56) with male predominance (56%). The prevalence of vitamin D deficiency was 70% and the mean serum vitamin D level was 23.94 (1.55) ng/ml. Amnestic variant of Alzheimer disease detected in 45% of our participants followed by vascular dementia (35%) and Parkinson disease dementia (10%). HIV associated dementia diagnosed in 6% of the participants. Hypertension was the most prevalent (45%) comorbidity reported in our dementia cohort. Severe vitamin D deficiency (under 10 ng/ml) was negatively association with disease severity (p=0.01) and increased age (p=0.003).

**Conclusion:** Vitamin D deficiency was prevalent in Ethiopian dementia patients. There are strong associations between severe vitamin D deficiency and dementia severity and increment in age.

### **Keywords**

Dementia, Alzheimer's disease, Vitamin D, Ethiopia





# The role of risk factors in development of cognitive disorders and cognitive decline in the Czech Republic: SHARE prospective study

### Dr Matej Kucera

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# **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aim:** Little is known about risk factors for dementia in Czechia. It is unclear whether these favourable trends that are observed in studies based in western countries hold true also in Czechia. Aim of this study is to investigate the association of risk factors for dementia with the incidence of dementia in Czechia, and determine the role of each risk factor.

**Method:** The survival analysis utilizing Cox regression is based on data from Survey on Health, Ageing and Retirement in Europe (SHARE) a multidisciplinary, cross-national study. Participants were included in the study in case they fulfilled following criteria: age of entry to the study 65 and higher, participation at least in two waves of SHARE, at least two measurements of cognitive functions. For the primary analysis, dementia was defined using adapted Lang-Weir classification (LW) utilizing available SHARE cognitive measures: immediate and delayed recall with including instrumental activities of daily living (IADL).

**Results:** Based on our preliminary results age (HR: 1.12, 95%Cl: 1.09-1.14), lower education (HR: 1.64, 95%Cl: 1.26-2.12), physical inactivity (HR: 2.1, 95%: 1.63-2.72), diabetes (HR: 1.71, 95%Cl: 1.35-2.17) and depression (HR: 1.47, 95Cl: 1.17-1.85) play the role of important risk factor in the dementia incidence.

**Conclusion:** This study represents a crucial step toward filling the knowledge gap regarding dementia risk factors in Czechia. The identified risk factors underscore the need for public health initiatives aimed at mitigating these factors to potentially reduce the incidence of dementia and improve the overall cognitive health of the population.

# **Keywords**

Dementia, mental health, risk factors, Czech Republic



# Co-Design of a Digital Gamified E-Resource to Aid Decision-Making that Supports Minimal Use of Restrictive Practice for People with Dementia in Nursing Home Settings.

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Queen's University Belfast, Belfast, United Kingdom

# **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

**Aims:** This project aimed to co-design a digital gamified e-resource to support staff decision-making regarding restrictive practice in nursing homes, specifically catering to individuals living with dementia, who are at a higher risk of restraint (https://play.restrictivepractice.co.uk/). The intervention was developed collaboratively, incorporating legal/ethical considerations, clinical guidelines, and stakeholder input.

**Method:** A sample of 874 participants, including 203 care home nurses who provide care to people with dementia in nursing homes and 671 nursing students, utilised the educational resource during Sept2022-March2023. Knowledge and self-efficacy regarding alternative strategies to restrictive practice for were assessed using Likert scale questionnaires. Pre/post audits (before and three months later) measured the impact on restrictive practice in 19 nursing homes in Northern Ireland specialising in dementia care. Further, 13 semi-structured interviews (SSIs) were conducted with nursing home staff and 5 focus groups with 49 student nurses to explore impact on resident care.

**Results:** Participants demonstrated a significant increase in knowledge and self-efficacy, with mean scores improving from 52% to 85% (p<0.001). Audit data revealed a reduction in mechanical restraints (bed rails, bumpers, lap belts) and environmental restraints (locked doors, windows) after the intervention (p<0.001). While chemical restraint reduced, this was not statistically significant. Qualitative data from interviews generated three key themes in relation to learning from the resource, "Learning: Innovating Insights and Facilitators," working with people with dementia to optimise practice, "Doing: Unleashing Practice Transformation," and sharing learning with colleagues, "Sharing: Catalysing Widespread Impact."

**Conclusion(s):** The gamified e-resource effectively enhanced knowledge and self-efficacy related to restrictive practice among care home nurses and nursing students responsible for providing care to people with dementia in nursing homes. Audits indicated a decrease in certain forms of restraint. Qualitative interviews underscored the resource's innovative learning approach, transformative impact on dementia care practice, and potential for widespread dissemination.

### **Keywords**

Dementia, Nursing Homes, Restraint, Restrictive Practice, Deprivation of Liberty, Co-Design, Gamification, Mixed Methods, Nurses, Nursing Students, Education, Asynchronous Learning.



# Dementia education for allied health professionals

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# **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

**Aim:** Using optometrists as an example allied health profession, describe the development of an online education course with Dementia Advocates, based on interview research. The course aims to address unmet learning needs of optometrists by 1) increasing knowledge of dementia, and 2) providing strategies to adapt clinical approach and communication to accommodate dementia. This breaks down known barriers to accessing eyecare, experienced by people living with dementia. Regular eye examinations, provided by optometrists as primary care, help detect and address preventable sight loss for people with dementia. Per the 2022 World Alzheimer's Report, looking after sensory health in dementia "creates environments and opportunities that enable people to be and do what they value throughout their lives".

**Methods:** We interviewed 13 people living with dementia and 15 carers about their experiences with eye tests for people with dementia. We interviewed 18 optometrists about their experiences of providing eyecare for people with dementia. Interview transcripts were analysed to bring these perspectives together in a framework. We shared our findings with Dementia Advocates to identify key messages for optometrists, to include within the training course. Dementia Advocates supported course development by reviewing the learning objectives, embedded quotes and case studies. The case studies are derived from the real world experiences of people with dementia and carers, shared during our research.

Results: The eight-hour course covered:

- Dementia types
- Communication difficulties
- Specialist vision testing
- · Adapting eye tests and management of eye problems to accommodate dementia
- Managing responsive behaviours that may arise in the eye clinic.

**Conclusions:** A high quality training course has been produced through involvement of people living with dementia, family carers, eyecare professionals and Dementia Advocates. This process could be applied to development of training for other allied health professions, who have a vital role in post-diagnosis support internationally.

# **Keywords**

allied health, optometry, education, consumer involvement



# Knowledge is the key to understanding - Free online e-learning in patient-centred and palliative care

#### Mrs Petra Tegman

Betaniastiftelsen, Stockholm, Sweden

# **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### Abstract

In one year more than 12 000 people working in elderly care and dementia care have finished our online training program in palliative care with very positive evaluation and feedback.

During the course, you will follow two persons and their families. One of them is diagnosed with Alzheimer's, and you get to follow the person from diagnosis to death learning best practices of care through tasks, lectures, and other pedagogical training methods.

The training aims to get more knowledge on how to support a person with a life-threatening disease and ensure he/she can have the best quality of life.

Even though more than 85% of the people taking the course claim to already have knowledge in palliative care, 80% evaluate they learned more through our online program.

Depending on computer habit, the course takes between 2-3 hours to complete. The course is designed to teach best practices och palliative care for the whole team and can easily be translated into any other language.

### **Keywords**

education, training, dementia, palliative care, quality of life



# STUDICODE - STepping-up Digital COmpetence in Dementia Education - A cross-disciplinary collaboration project

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# **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

In response to the aging of the population, dementia has emerged as a major health and social problem all over Europe. Multiple professions must work together and coordinate their efforts for effective personcentered dementia care. Nevertheless, students in the appropriate socio-medical fields are not always well trained for these kinds of cross-disciplinary collaborations. Online courses built on cutting-edge pedagogical frameworks and e-learning methods may help bridge this knowledge gap.

The STUDICODE initiative is a result of this collaboration between several higher education institutions: the Memory Centre Bratislava (Slovakia), the University of Ljubljana (Slovenia), the Technical University of Munich (Germany), and the University of Medicine and Pharmacy "Carol Davila" (Romania). STUDICODE is a cross-disciplinary, comprehensive, and multilingual online course on dementia. The initiative also aims to improve instructors' digital competency to speed up the creation of comparable medical-themed MOOCs (massive open online courses).

STUDICODE was one of the first online courses at our university. The course was optional, without credits for completing it, but 131 medical students enrolled and completed the entire course on dementia last year.

According to the students feedback, 93% of them stated that the scope of topics featured in the course was "exactly right", while 92% of students stated that the depth of information was "exactly right". Regarding the overall grade awarded by the students of the course, 73% awarded grade A and 24% grade B. No student rated the course with grade D or below. Regarding the various media formats, students enjoyed their diverse usage. 69% stated that they found the media formats useful. Furthermore, 57% of students described the media formats as "entertaining". After completing the course, all students who responded to feedback reported having a clearer picture of dementia-72% in a significant way.

STUDICODE is funded by the European Union through the programme "Erasmus+".

# **Keywords**

cross-disciplinary, collaborations, dementia, online, course



# **Understanding Lived Experience and Care Partner Journeys Through a Culturally Competent Lens**

### Ms Mary Chi Michael

Philadelphia, Philadelphia, USA

# **Topic**

**Dementia diagnosis, treatment, care and support:** Importance of cultural context training for carers/provider

#### Abstract

**Objective:** To explore how dementia journeys differ across culturally and socioeconomically diverse populations, with a particular focus on understanding how/when behavioral symptoms associated with dementia are identified and addressed and how/when the responsibilities of caregiving shift within each community.

**Background:** In 2021, the Global Council on Alzheimer's Disease (GCAD) conducted research on lived experience and care partner journeys. Since, GCAD has expanded this research to include the experiences of individuals from historically underrepresented populations, specifically LGBTQ+, Black, Hispanic/Latino, and Asian communities to identify how these journeys diverge across communities.

**Methodology:** To understand the journeys and experiences of culturally and socioeconomically diverse communities living with dementia, this project undertook qualitative primary research complemented by secondary research. Primary research included one-on-one interviews with people living with dementia and care partners. Secondary research explored how literature did or did not support the themes and ideas of the qualitative research.

**Results:** Results account for and map distinct journeys members of each community experience. These journey maps illustrate how one community's journeys might overlap and diverge compared to others. The maps capture the challenges each community faces, resources that have been developed, and how care is managed along the disease progression.

**Conclusion:** The research identifies several differences in the dementia experience both among and between each community, including: medical inequity, bias, and unequal care and treatment; how care is managed both institutionally and in the home; impacts of the presence or absence of traditional family care structures; different manifestations of stigma surrounding dementia; and varying availability of resources for living well with dementia.

The project concludes with a call to action that outlines how the dementia community can better support people affected by dementia from underrepresented communities; it also emphasizes the importance of applying culturally competent approaches to understanding these journeys.

### **Keywords**

Cultural competence, lived experience journey, care partner journey



# Development of Culturally Sensitive Dementia Caregiving Psychoeducation Intervention: Views from Chinese Care Partners on iSupport Adaptation

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# **Topic**

**Dementia diagnosis, treatment, care and support:** Importance of cultural context training for carers/provider

#### Abstract

**Aim:** There is soaring evidence that psychoeducation intervention could facilitate the care partners of people with dementia (PWD) to provide daily care and reduce caring stress, and online psychoeducation allows care partners who are working or living with the PWD to learn in a time- and space-flexible manner. This study aimed to understand the cultural preference of Chinese care partners of PWD in Hong Kong regarding an online psychoeducation intervention and to explore elements that would facilitate their self-learning.

**Method:** This study adopted a qualitative descriptive design. Chinese care partners of PWD in Hong Kong were invited for individual interviews or focus groups after they studied the translated contents of iSupport for Dementia, an online psychoeducation programme developed by The World Health Organization. The data were analysed with thematic analysis. This study was funded by the National Foundation for Australia-China Relations, Australian Government.

**Results:** Twenty care partners of PWD were interviewed. Five themes were identified: (1) in addition to language translation, the adaptation of case studies should also encompass cultural factors so that the scenarios tallied with the everyday experiences of Chinese elderly; (2) foreign domestic helpers were significant stakeholders in dementia care in Hong Kong, the education should also address their learning needs; (3) when the care partners' families lived with the PWD, the changed behaviours could have profound caring impacts, underlining the importance of incorporating management of changed behaviours and relaxation exercises as key learning components; (4) Chinese culture posed challenges to engaging the PWD in discussion about advance care planning; and (5) it was important to include interactive forum and multimedia materials to facilitate self-learning.

**Conclusion:** Dementia caregiving psychoeducation should be culturally sensitive and consider the needs of various caring stakeholders so that the intervention components could best facilitate the self-learning of the care partners.

### **Keywords**

dementia, care partner support, isupport, cultural adaptation



# **Every Story Matters**

Mr Norman Williamson<sup>1</sup>, Mrs Joanna Boddy<sup>2</sup>

<sup>1</sup>Alzheimer Scotland, Glasgow, United Kingdom. <sup>2</sup>NDCAN Member, Glasgow, United Kingdom

# **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Everyone has a story, and everyone's story matters. This is the ethos of Scotland's two active voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN). Both groups are member led with the SDWG representing people living with dementia; and NDCAN for unpaid carers. By focusing on their personal dementia stories, the members will often share their experiences to help change how dementia is understood.

A recent short film was produced featuring one SDWG member who portrayed his story emphasising the message that dementia is just one thing about a person – and not everything'. In the film the member explains that people with dementia can learn new things, continue with work and hobbies, and live a full, enjoyable life.

From a carers perspective, NDCAN members share their stories through personal 'story blogs' to raise awareness of the challenges that families can face. Their stories include various themes on the impact of caring such as: having to give up work and move house to support a parent; caring for a loved one whilst working; and on a more positive note, how joining NDCAN gave one particular member a new purpose in life.

SDWG & NDCAN members are aware that everyone's dementia story is different, however they hope that sharing their experiences will inspire others to do the same, and moreover, open up the conversation about dementia and provide their peers with comfort in the knowledge they are not facing dementia alone.

### **Keywords**

different, hobbies, full, team





#### Art Exhibition- ALZHEIMER: The hidden memories

#### **Mrs Ingrid Tatiana Wellington**

AFAPADEA, PANAMA, Panama. ALZHEIMER IBEROAMERICA (AIB), PANAMA, Panama

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Since 2019, Alzheimer's Disease Association – (AFAPADEA)-Panama, launched Dementia Friends program to create awareness of dementia and more supportive of people who live with dementia and their family. Since there isn't a National Dementia Plan in Panama, Alzheimer association had been dedicated to create friendly communities including different kinds of dementia friendly actions suchs as: creating dementia friendly public and private institutions, supermarkets, approaching local government authorities and Ministry of Heath and others.

In this presentation I will discuss about art exhibition called Alzheimer: The hidden memories which use arts forms to raise awareness and consciousness about brain health, dementia care, to understand the feelings and emotions of a person living with dementia and how an artist give the concept of Alzheimer's disease through visual art. The art exhibition is well organized in several sections such as: Tower of books in which the books at the top are burned representing the short term memory, a brain made with coaxial cable (some of them cutted) showing the disconnection of neurons when the brain is affected by neurodegenerative disease, a maze with a transparent image, a chair sorrounding by black cloth and a light illuminating the chair representing how a person living with dementia may feel without family support.

This presentation will close by presenting testimonies: Wife – "All the paintings about feelings let me know my husband feels, so I need to recognize his feelings". Geriatric Doctor: "There is a great opportunity for families and colleages to learn more about dementia thorough art. It's a different way to see and understand it", Daughter: "Never is too late, but I would like to learn it before my mother dies". Psychology student: "I am so excited and I will recommend to everybody.

#### **Keywords**

Person, Hope, Awareness, Quality Dementia Care, Visual Art, Family, Community, Learning,



### Dynamics in Dementia's perception and care provision in France between 2020 and 2023: evidence from Elders cohort

Dr Nina Zerrar, Ms Christine Tabuenca

Fondation Médéric Alzheimer, Paris, France

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Every three years since 2012, Médéric Alzheimer Foundation produces a wave of Elders survey (survey on longevity, dependency, risk and support). 2023 is marked by a new wave of the survey. Data collection tooks place between march, 28th and June,12th 2023 and was done by Kantar Public using a mailed questionnaire send to 10 000 individuals. This targeted sample was selected by targeted every respondent to one previous wave and a refreshment sample which insure the representativity to then population aged between 40 and 79 years old of the whole sample at each wave.

Final sample included 6,162 individuals aged between 40 and 79 years old with among them 1,433 carers of a parent or a parent in law and for 485 of them, care provided concerns a parent/parent in law with Dementia. These answers are analysed in the 4th Fondation Médéric Alzheimer's barometer: "Longterm care, Alzheimer's condition and caregiving: what do French people have to say?'". The later was the first one after covid and the French nursing home crisis.

As a starting result, Dementia is still part of daily life of the French aged between 40 and 79 years old. In fact, 1 out 2 respondents has one or more relatives living with Dementia. Although this exposition favours concern about late life, several indicators suggest a decrease in long-term care and Dementia awareness since 2020.

Then, our study focuses on informal care with 3 main

**Results:** (i) care duration has significantly increased between 2020 and 2023, (ii) support for pwD still more intense in terms of help provided and its frequency, and (iii), informal carers' health has significantly worsened over the last three years. This is consistent with their rising support and thus is of even greater concern to carers of pwD.

#### **Keywords**

Barometer, cohort in general population, Dementia perceptions, informal care, health consequences, carers at work, LTC planning



### Good neighbors - a collaboration between an acute hospital and prison to support prisoners living with dementia

Mrs Jo James<sup>1,2</sup>, Mrs Ruby Fitzhenry<sup>1</sup>

<sup>1</sup>Imperial College Healthcare NHS Trust, London, United Kingdom. <sup>2</sup>Jaya Mental Health, London, United Kingdom

#### **Topic**

Dementia awareness: Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

From 2002-2020 the number of prisoners over 50 has increased 243% and 8% of them have dementia (1). As the growth is often attributed to the work on historical sex crimes these prisoners are a particularly marginalized group.

We are a nurse led dementia team working at Imperial College Healthcare NHS Trust. One of our hospitals is next door to a Category B prison. Having cared for a prisoner in hospital we approached the prison to explore how we could work together.

We have established a strong relationship with the prison healthcare team by initially offering training sessions on dementia. At first, they stated that they did not have an issue with any prisoners, but after the training, they referred a prisoner to us and we were able to provide a care plan and support the patient.

Our relationship is evolving as staff begin to trust us. We are now being asked to include the prison officers in training, are receiving more referrals, are being asked to help develop their own dementia pathway and are receiving alerts when their prisoners are admitted to hospital.

In an ideal world, every service would have dementia specialists, but the reality of scarce resources means that most prisons do not. By sharing our resources with our neighbors we have created a model which costs little and provides access to services for a group of people with dementia who are often excluded and ignored.

House of Commons Justice Committee (2020) Ageing Prison Population. HOC. London

#### **Keywords**

Dementia, Prison, Acute Hospital, Inclusion, marginalized



#### The Hearing Loss & Dementia Connection: The How, What, & Why

#### Dr Jaime A.B. Wilson

Wilson Clinical Services, PLLC., Tacoma, WA, USA

#### **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

In this presentation, top-selling author, Dr. Jaime A.B. Wilson, embarks on a fascinating and entertaining journey on the what, how, and why of the dementia and hearing loss tie-in. Those of us with hearing loss – including our loved ones and esteemed healthcare providers – must be aware of the 24% increase that hearing loss adds to dementia risk. Dr. Wilson discusses what we can do to protect ourselves against the disease of dementia while maximizing the quality of our lives during the Golden Years. This presentation offers a rare and unique perspective into the world of dementia through the lens of hearing loss.

#### **Keywords**

deaf, hearing loss, hard of hearing, late-deafened, late-onset hearing loss, dementia, healthcare, aging, Alzheimer's



#### Architecture through the lens of living with dementia

#### Ms Emily Tan Tan Ong

Dementia Alliance International, Singapore, Singapore. Alzheimer's Disease International, Singapore, Singapore

#### **Topic**

Dementia awareness: Environment and architecture for dementia

#### **Abstract**

By 2050, the world's population of people aged 60 years and older will be 2.1 billion and 153 million people are expected to be living with dementia. While dementia brings a range of difficulties it also compounds the disabilities that already tend to worsen with age and poor health. Yet, these groups and people with some form of disability which is approximately 1 billion, are often left out in architectural design. The attitude towards allocation for ramps in built environment is more of fulfilling construction protocols and bylaws.

In this presentation, "Architecture through the lens of living with dementia," I will touch on disablement and exclusion impact of ableist architecture on the lives of people living with dementia. When I was diagnosed with dementia the greatest fear that I have is being imprisoned and disabled by ableist design. A design that says, "You need to meet the expected ability standard to enter, to enjoy and to use the facility." A design that forgets a human body can age and susceptible to injury or changes. While accessibility is important, there is more than just removing physical barriers to be able to use and enjoy the environment.

#### **Keywords**

Architectural design, dementia, ableist design



#### Not You but We: Making New Taipei City Dementia-Friendly

Miss Jiun Tz Chian, Miss Hsuan Ting Lin, Mrs Ling Pei Liu, Mrs Feng Yu Wu, **Dr Che Yu Chen**, Mrs Chen Shu Kao, Dr Chou Ran Chen

Department of Health, New Taipei, Taiwan

#### **Topic**

Dementia awareness: Dementia friendliness and inclusivity

#### **Abstract**

New Taipei, Taiwan's largest city, has a population exceeding four million, including 700,000 seniors and 48,000 people with dementia (PwD). Facing disparities in resources, the city adopted a bottom-up and collaborative approach and learned from PwD to create user-centered policies to become more dementia-friendly, inclusive, and supportive.

**Planning:** Over 300 stakeholders, including PwD, their families, physicians, caregivers, local organizations, and government representatives, developed an action plan through dialogue in regular open-space meetings. New Taipei City is the first in Taiwan to implement a second action plan.

**Implementation:** The deputy mayor convened regular meetings with all 16 bureaus to monitor progress and share results.

#### **Results:**

**Literacy:** We actively recruited organizations to provide dementia literacy education to different age groups. The city has Taiwan's highest Dementia Friends training completion count, with 310,783 people (7.7% of the population) having completed the training.

**Care networks:** The city replaced screening with referrals, connected over 1,600 community clinics and pharmacies to identify potential dementia patients, and established a green corridor to facilitate the diagnosis process. Our shared-care centers have managed 20,476 cases and connected PwD with services and resources.

**Environment:** Cross-domain private and public agencies collaborated to establish guidelines for a dementia-friendly environment.

**Social prescription:** We collaborated with museums, libraries, factory tours, etc. to enrich the lives of PwD and their families and encourage active participation in community activities. **Innovation:** We launched the Village of Ageless Wisdom, a dementia-friendly demonstration community, and applied our experience to other communities. LOHAS Brain Bus 2.0 has been bringing training and individualized professional interventions to rural areas.

New Taipei City achieved the "7-7-7 Goals of Dementia Friendliness" in July 2023 through multiple strategies aimed at creating a friendly and inclusive city. With adequate support, PwD and their families can live independently with peace of mind.

#### **Keywords**

Dementia, Dementia Friendliness



#### **Dementia Friendly Dentistry**

#### Mr Ian Grant Sherriff

Plymouth University faculty of Health, Plymouth, United Kingdom

#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

What Is a Dementia Friendly Dentist?

An inclusive Dementia Friendly Dentist in both rural and urban areas creates an enabling environment, engaging with people living with dementia, their families, and carers. This makes it possible for people living with dementia to continue to have compassionate, individualised dental health care. A Dementia Friendly dental practice will enable people with dementia to have a sense of belonging and feel a valued part of a community and civic life. (Source: National Dementia Declaration 2012). An inclusive Dementia Friendly dental practice works to sustain and improve the dental quality of life for people living with dementia which will reduce the impact of the lack of dental care, stigma, isolation, and loneliness. Dementia Friendly dental practices need to be flexible, adaptable, and responsive to the different needs of people living with dementia and their carers. It is important to ensure that people living with dementia can continue to enjoy the previous dental support they had been receiving. This paper, talk will suggest some dental dementia friendly actions within three broad areas that dental practices should consider helping improve the experience and quality of care for people living with dementia and their families and carers. It is important to remember that it may not be possible to achieve everything suggested in the short term. However, every practice can easily achieve many of the suggestions to improve their patient's experience. We suggest that these ideas are discussed at dental team meetings; with a designated dementia lead undertaking the work and reporting back to the team.

Ian Kenneth Grant Sherriff B.E.M. MA. DMS. CQSW. Dip Cll Academic Partnership Lead for Dementia Primary Care Group Clinical Trials and Population Studies Faculty of Health University of Plymouth

#### **Keywords**

Dementia, Dentistry, Awareness, Diagnosis



### Delivering a Virtual Support Group for Caregivers of Persons with Dementia - The Experience of Alzheimers' Ghana.

Dr Sally Yalley<sup>1,2,3,4</sup>, Dr Kwaku Sarfo Manu<sup>3,5</sup>, Mr Venance Dey<sup>3</sup>, Prof Roman Romero Ortuño<sup>1,2</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

With the rise in dementia diagnoses globally, caregivers face unique challenges in regions with limited resources. At Alzheimer's Ghana, we introduced a virtual support group for caregivers, which involves a chatroom on WhatsApp, and structured monthly Zoom meetings.

Support groups offer a valuable platform for caregivers to connect, share experiences, and exchange practical advice. The virtual format circumvents geographical barriers and enhances accessibility for caregivers who may lack transportation options.

The meetings are facilitated by a professional, and provide education and training on relevant topics which include what dementia is, how to provide dignified care, using music and artbased interventions, dealing with challenging behavior, and navigating caregiver stress. Caregivers also share their experiences and challenges in these meetings and on the WhatsApp platform, and are furnished with infographic, text and video resources.

However, challenges such as unreliable internet connectivity, limited digital literacy among older caregivers and high costs of internet data highlight the need for tailored technological interventions and funding opportunities.

Areas of future exploration include introducing a parallel group only for persons with dementia, and starting satellite groups in local languages to improve accessibility, as Ghana is home to a myriad of diverse local languages. Exploring the approach of co-production, where some sessions are led by caregivers could promote openness and a more relaxed atmosphere for caregivers to share their experiences and challenges.

In conclusion, equipping caregivers with relevant training and support is essential for ensuring dignified dementia care and promoting dementia-friendly communities in Africa.

#### **Keywords**

dementia, care, support groups, caregivers, informal, virtual, Africa.





#### Investigating the effectiveness of cascade training workshop on the level of knowledge and attitude of managers of care homes in provincial institutions of Welfare Organization with emphasises on Person Centered Care

Mrs Masoome Salehi<sup>1</sup>, Dr raziye sadat hosseini<sup>2,3</sup>, Dr Mohammad Reza Hossaini<sup>4</sup>, Mrs mehrzad babaei<sup>5</sup>, Mrs manije ahmadi<sup>6</sup>, Dr elahe zaheri<sup>6</sup>, Dr Mina Ahmadzadeh<sup>7</sup>, Mrs bahare Mohammad jafar<sup>7</sup>, Mrs somiye barzegar<sup>7</sup>, **Mrs Faraneh Farin**<sup>7</sup>, Mr mehrdad khansari<sup>8</sup>, Mrs fateme naghne<sup>7</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Introduction:** Research shows that dementia is the seventh leading cause of death in the world. Dementia affects individuals, families, healthcare systems and socio-economics of countries. It is estimated that about 10% of older adults will develop dementia on the world and 7.90% in Iran. Due to lack of knowledge about dementia, care staff faces many challenges in care settings, across the country. To address this shortcoming, Iran Dementia & Alzheimer's Association(IDAA) supported by World Health Organization, engaged provincial Alzheimer's associations and collaborated with the Welfare Organization to run the project.

**Objectives:** Train care staff

Train family carers

**Method:** A technical committee was formed comprised of university professors and experts from IDA A. The content of the action plan was approved and the educational packages were developed according to the WHO's guidelines namely Mental Health Gap Action Program and ISupport. The course included a package for 40 hours of training with 9 main topics. A shorter version for 12 hours of training was also developed for the use of trainees in their future provincial training.. Using cascade training method to reach optimal results, the workshop trained candidates from fourteen provinces who were approved by Welfare Organization. The trainees in turn trained care staff and family carers in their respective provinces. Pretest and post test questionnaires including 20 questions were distributed among participants before and After five days of workshop to assess the level of knowledge and attitude and evaluate the impact of training.

**Results:** The results show an increase in awareness and improvement in knowledge and attitude among participants which can impact the quality of person centered care in care settings and homes.

**Conclusion:** The effectiveness of dementia training workshop on participations has empowered and IDDA to continue to planning another workshop in the forthcoming year.

#### **Keywords**



# The Difference in Burden Experienced by Male and Female Caregivers of Dementia Patients in Lebanon: A Cross-Sectional Study

Prof Monique Chaaya, Ms Mayssan Kabalan

American University of beirut, Beirut, Lebanon

#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aims:** To assess the burden of care experienced by caregivers of dementia patients and its association with psychological well-being according to gender.

**Methods:** This was a cross-sectional phone survey of dementia patients' caregivers from various locations in Lebanon, conducted in 2019. The sample consisted of 50 female and 11 male informal caregivers, in daily contact with the patient. The sample was conveniently selected and identified through two main non-profit organizations. The patient and the caregiver's sociodemographic information were recorded. The psychological distress was measured with General Health Survey Questionnaire (GHQ 12) whereas the burden of care was measured using the Zarit Burden Interview (ZBI 22).

**Results:** The mean age of the 61 caregivers was 51 ±11 years, with more than half being sons or daughters of the patients. A large proportion reported a severe level of overall burden (41 %) with no gender difference. Only Feeling of life loss control since relative's illness was substantially higher among females. 70.5% of caregivers experienced moderate to severe distress, being significantly higher in females. Severe burden among females was significantly associated with 15.55 higher odds of distress compared no or mild to moderate burden. No association was found among male caregivers.

**Conclusions:** Both male and female caregivers are burdened by the care they provide to their relatives who live with dementia. However, females are more affected and are more distressed with higher burden. This could be explained by the different gender roles imposed by the society on its members. Caregivers should be part of a support system to improve their coping skills, reduce their stress, and decrease the burden. A larger sample size is needed to better understand underlying mechanisms and identify necessary confounders.

#### **Keywords**

caregiver, carer, dementia, burden of care, distress





#### Common Narratives Among Puertorrican Caregivers of Persons Diagnosed with Alzheimer's Disease: The Experience of Community-Led Support Groups for Caregivers of Persons Living with Alzheimer's Diseases in Puerto Rico

Dr Francisco Javier Parga, Mrs Edna Rodriguez-Lozada

Puerto Rico Alzheimer's Association, San Juan, Puerto Rico

#### **Topic**

**Support for dementia carers:** Informal carers support – pre, during and post

#### **Abstract**

Alzheimer's Disease (AD) has increased substantially in Puerto Rico over the past twenty years. In 1999 AD was not listed among the first fifteen causes of death. Before 1999 AD was not among the top 15 causes of death. By 2008, AD was the fourth cause of death with 1,591 deaths and an adjusted rate of 38.0 (Puerto Rico Institute of Statistics, 2010). The most recent statistical report (Puerto Rico Department of Health, n.d.) indicates that for year 2021 AD continued to be the fourth cause of death in the Island with a reported rate of 86.8. The Puerto Rico Alzheimer's Disease Association (PRADA) provided educational and support services for 40 years. Among them, the Association has maintained an average of 35 groups for over 25 years. Support groups have been a key source of sustenance for many caregivers around Puerto Rico.

**Aim:** This research sought to identify the most common needs as expressed by participants as well as group facilitators.

**Method:** Group facilitators and participants attended one of ten focus groups conducted around Puerto Rico. Sociodemographic data was obtained for all participants. Through a semi-structured interview, group participants identified and prioritized topics and themes that were relevant to the situations they confronted while providing services to persons with AD.

**Results:** Fifteen priority topics were identified. Differences in responses and priorities between facilitators and support group participants were listed.

**Conclusions:** Identified topics were examined to establish a hierarchy of importance as a reference for future facilitators to use as guides to establish their work plans. There were differences between the identified topics for each group of participants.

#### **Keywords**

Support groups, topics, priorities for participants



### The Space Between: Understanding the Experience of Nonbinary Persons with Dementia. A qualitative exploration.

Ms Dáithí Clayton<sup>1</sup>, Prof Phil Harper<sup>1</sup>, Mr John Hammond<sup>2</sup>

<sup>1</sup>Newman University, Birmingham, United Kingdom. <sup>2</sup>Brighton and Sussex Medical School, Brighton and Hove, United Kingdom

#### **Topic**

Dementia research and innovation: LGBTQI+ and dementia

#### **Abstract**

While much research has been done on the experiences of people with dementia, little is known about the experiences of non-binary individuals with dementia who identify as neither exclusively male nor exclusively female. This research project is being led by nonbinary people with dementia with support of allies in the field of dementia studies.

The objective is to explore the experiences of non-binary individuals with dementia and identify unique challenges related to their gender identity.

Using a qualitative approach to data collection and analysis, Semi-structured interviews will be conducted with participants. Interviews will be audio-recorded and transcribed verbatim. Thematic analysis will be used to identify patterns and themes. We aim to capture the personal perspectives of participants, highlighting the subjective nature of their experiences.

This research will be conducted in accordance with ethical principles and guidelines involving human participants. Informed consent will be obtained from all participants, and confidentiality maintained throughout. The Dementia Enquirers Gold Standards for Ethical Research (https://www.dementiavoices.org.uk/wp-content/uploads/2020/07/The-DEEP-Ethics-Gold-Standards-for-Dementia-Research.pdf) will be used as a guiding principle.

Expected outcomes include a better understanding of the experiences of non-binary individuals with dementia, as well as the unique challenges related to their gender identity. This information may be used to inform the development of more inclusive and culturally competent dementia care practices.

This research aims to fill a gap in the literature by exploring the experiences of non-binary individuals with dementia. We can work towards more inclusive and culturally competent dementia care practices that meet the diverse needs of individuals with dementia.

#### **Keywords**

Nonbinary, LGBTQI+, dementia, gender, sexuality, identity, ciscognonormativity





### Exploring the experiences of LGBTQ+ people living with dementia: It's time to get creative!

#### **Mr John Hammond**

Brighton and Sussex Medical School, Brighton and Hove, United Kingdom

#### **Topic**

Dementia research and innovation: LGBTQI+ and dementia

#### **Abstract**

**Aims:** Historically, studies have excluded the voices of LGBTQ+ people living with dementia and focused instead on their care partners or health and social care professionals. There is a need to better understand how to engage LGBTQ+ people within research to elicit knowledge on their experiences of dementia and how they can be supported to live well with the condition. This presentation draws on two bodies of work to provide insights and recommendations when conducting research with this minoritised population.

**Method:** A scoping review was undertaken to provide an overview of the creative methods used within research to elicit the voices of LGBTQ+ people. This data was supplemented with the researcher's own reflexive field-notes that were taken as part of a qualitative study aimed at exploring the dementia diagnostic experiences of LGBTQ+ people.

**Results:** The scoping review confirmed a dearth of research that explicitly engaged LGBTQ+ people. However, it highlighted the potential that creative methods such as 'Photovoice,' which draw on Participatory Action Research methodologies, may offer when engaging this population. Reflexive field-notes, taken as part of the qualitative study, provided additional information that suggested LGBTQ+ people would welcome sharing their experiences of living with dementia and embrace creative methodologies that enable them to take control of their narrative and leave a lasting legacy for future generations.

**Conclusion:** Creative methodologies such as 'Photovoice' are likely to provide a valuable tool for ensuring the voices of LGBTQ+ people are heard within the dementia care agenda. However, it is essential that they are employed in a way that facilitates the engagement of LGBTQ+ people and empowers them to tell their story.

#### **Keywords**

LGBTQ+, creative methodology, lived experience



#### Living with violence in Colombia: the risk of developing mental health problems and dementia among older adults living with violence throughout their lives

**Prof Mark Benjamin Gabbay**<sup>1,2</sup>, Prof Maria Isabel Zuluaga<sup>3</sup>, Prof Gabriel Saldarriaga Ruiz<sup>3</sup>, Dr Erika Maria Montoya<sup>3</sup>, **Dr Clarissa Marie Giebel**<sup>1,2</sup>

<sup>1</sup>University of Liverpool, Liverpool, United Kingdom. <sup>2</sup>NIHR ARC NWC, Liverpool, United Kingdom. <sup>3</sup>Universidad de Antioquia, Medellin, Colombia

#### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

#### **Abstract**

**Aim:** Generations of the poorest among Colombian society particularly in (semi)rural and peri-urban settings, have been exposed to, and displaced by, endemic violence for 70 years, affecting ~10m people (20% total population). In 2022, 12.5% (1.2m) were older adults living with the health and socioeconomic consequences, losses and life-changing disruptions. Our joint Colombian UK-funded project in coastal Antioquia explores ways to co-produce and pilot an intervention to help mitigate impacts older-adults' mental-health and wellbeing. The survey we report explores their burden of ill-health and adversity, mental health and wellbeing, and compares the experiences of this population involved in the programme, with other recent large surveys among older adults in Colombia also living through 'La Violencia'.

**Methods:** We compared our 2022 older-adults survey in Turbo( n=611) with 2016 (0.5m) survey findings from three other Colombian regions with different exposures to 'La Violencia'. These surveys measured Cognitive status, Functionality, Autonomy, Depression, Anxiety, Alcohol-use, Well-being, Social support, Loneliness, Nutrition and Maltreatment plus demographics. We used probability cluster two-stage sampling to enhance representativeness.

**Findings:** Older adults surveyed are not familiar with the concept of Mental health, rates of 'depression' (5-28%) and 'anxiety' (4-21%) were lower than anticipated. However a very high proportion in coastal Antioquia had at least some cognitive deficit (62%), much higher than recent comparable Colombian older adult surveys report (1.3-5.1%). Most respondents were living in significant poverty with low educational attainment, low or minimal income, low nutrition, poor housing and social isolation. Reported elder abuse rates ranged from 4-30% across sites.

**Discussion:** The survey findings confirm high rates of vulnerability among older adults living with the severe consequences of La Violencia upon mental-health. Our project co-producing and delivering affordable and sustainable interventions seeks to improve mental health and wellbeing, self-esteem and belonging, within a society that largely neglects older adults.

#### **Keywords**

Survey, older adults, mental health, dementia, violence



# Recruiting people living with dementia (including those who lack capacity to consent) remotely vs. in-person: learning from the Dementia PersonAlised Care Team (D-PACT) feasibility study during COVID-19

**Dr Tomasina M Oh**<sup>1</sup>, Dr Crispin Musicha<sup>1</sup>, Dr Saqba Batool<sup>2</sup>, Dr Leanne Greene<sup>3</sup>, Dr Hannah Wheat<sup>1</sup>, Prof Siobhan Creanor<sup>3</sup>, Prof Richard Byng<sup>1</sup>

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#### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

#### **Abstract**

**Aim:** Recruiting people living with dementia who lack capacity to provide informed consent is challenging, and the voice of this group remains under-represented in research. The Dementia PersonAlised Care Team (D-PACT) study has developed and is evaluating the value of a dementia support worker based in primary care providing personalised support to people with dementia and their care partners. In Phase 1, we developed and tested our intervention together with a person-centred recruitment and capacity judgement process to allow inclusion of people without capacity to consent. Recruitment during Phase 1 was interrupted by the first UK COVID-19 lockdown (March 2020) and, following adaptations, re-started in September 2020. This resulted in two recruitment phases, one that was in-person pre-pandemic (September 2019-March 2020) and another that was remote during the pandemic (Sept 2020-March 2021).

**Method:** We compared quantitative recruitment data (proportion recruited out of those approached; rate of recruitment per week) before (in-person recruitment) and during the pandemic (remote recruitment). Qualitative interviews about participants' (n = 14) experience of remote recruitment were also conducted and analysed using a thematic analysis.

**Results:** We recruited a similar proportion out of those approached in-person (9.9%) vs. remotely (9.5%). Recruitment rate pre-COVID was lower than during the pandemic (3.58 dyads per month vs. 5.73). Qualitative interviews indicate that remote methods (e.g. verbal consent) are acceptable to participants. However, preferences (remote vs. in-person) are linked to need, circumstances or disposition.

**Conclusion:** Our findings suggest that remotely recruiting people with dementia, including those without capacity to consent, is comparable to in-person methods, acceptable and even preferred by some participants. We propose that adopting a flexible hybrid approach could increase inclusion of more people with dementia (e.g. those who prefer remote methods or live in remote areas) in research.

#### **Keywords**

Recruitment, remote recruitment, lack of capacity to consent, dementia, COVID-19, person-centred, inclusion, inclusivity



### Technology facilitated African & African Caribbean reminiscence in dementia Care - Bridging the gap.

#### **Mr Carl Case**

Cultural Appropriate Resources, Sheffield, United Kingdom

#### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

#### **Abstract**

People from African and African Caribbean descent are 22% more likely to develop dementia than their white friends and neighbours, also living for shorter periods and dying at younger ages. (UCL. Sept 2023).

The 'Windrush Memory App' co-created by African Caribbean people living with dementia (PLWD) capturing, preserving, digitising, community and cultural heritage stories, including the interactive 3D Virtual Tour of the Windrush Museum Exhibition.

A heritage-based series of digital cognitive stimulation and reminiscence resources, which from the comfort of 'home', on their favourite devices and without headsets, individuals globally will be able to independently actively engage, or with care-partners and family members.

Designed to also support predominantly Elders, helping them develop new digital skills, connections and interests, triggering discussing events and experiences from their cultural past, designed to evoke memories, stimulate mental activity and improve person's well-being.

Attached videos to the various vintage artefacts, will be of PLWD sharing why and how they played an important role in their lives, in the Caribbean or once settled in the UK

The App will help people: Feel more confident in their abilities, Slow down the decline of cognitive abilities, Return them to story-teller pedestal, Digitally preserve family stories

For many care workers, a cultural social distance exists between them and certain residents, they will now also have an engaging, accessible, culturally responsive intervention serving to reduce this cultural deficit.

The accompanying, 'Dementia Journey' series of life-story videos with African and African Caribbean PLWD sharing their experiences in; Ways to Minimise the development of Dementia, How early Presentation can lead to Better Outcomes, ways to Live Well, Support for Care Partners, Value of Early End of Life Planning for All

#### **Keywords**

Increasing inclusivity, diversity, access, African & African Caribbean care partners, reminiscence, Windrush, Virtual Museum Tour, Memory App and health disparities.



### Sex differences in the prevalence of mild cognitive impairment and dementia, and their risk factors, in Bengaluru

Ms Aparna Venugopal<sup>1</sup>, **Prof Michelle Mielke**<sup>2</sup>, Dr Avanthi Paplikar<sup>3</sup>, Ms Feba Anna Varghese<sup>1</sup>, Mr Rakshith Maneshwar Hoskeri<sup>1</sup>, Dr Faheem Arshad<sup>1</sup>, Dr Girish Nagaraja Rao<sup>1</sup>, Dr Neelum Aggarwal<sup>4</sup>, Dr Suvarna Alladi<sup>1</sup>

<sup>1</sup>National Institute of Mental Health and Neurosciences, Bangaluru, India. <sup>2</sup>Wake Forest University School of Medicine, Winston-Salem, USA. <sup>3</sup>Chandrasekhar Institute of Speech and Hearing, Bangaluru, India. <sup>4</sup>Rush University, Chicago, USA

#### **Topic**

Dementia research and innovation: Women and dementia - sex and gender in research and policy

#### **Abstract**

**Aims:** To assess whether the prevalence of mild cognitive impairment (MCI) and dementia differs by sex in urban Bengaluru and whether risk factors for MCI and dementia differ by sex.

Methods: A community-based, cross-sectional study was conducted in urban Bengaluru between January 2021 and December 2021. The study team performed household enumeration to identify individuals who were ≥ 60 years old. Neurologic, neuropsychological, and functionality tests and a cardiovascular risk profile questionnaire were administered to all participants. Participants were categorized as having no cognitive impairment, MCI, or dementia. MCI was diagnosed based on Petersen's criteria (2004) and dementia was diagnosed based on DSM-IV criteria (1994).

**Results:** Of the 1,234 participants, 665 (53.9%) were female and 569 were male (46.1%). Males were slightly older (mean (SD): 72.0 (8.68) vs. 70.5 (7.79) years, p=0.001) and had more years of education (mean (SD): 13.3 (4.65) vs. 9.9 (5.75), p<0.001). Of the 1,234 participants, 80 had MCI (6.5%) and 24 (1.9%) had dementia. More males than females had MCI (7.9% vs. 5.3%, p=0.06). In contrast, males were less likely to be diagnosed with dementia (1.1% vs. 2.7%, p=0.04). Males had a higher prevalence of heart disease, whereas females had a higher prevalence of hypertension.

**Conclusions:** The prevalence of MCI and dementia differs by sex in Bengaluru, as does the prevalence of vascular risk factors.

#### **Keywords**

sex differences; mild cognitive impairment; dementia; vascular risk factors; India; epidemiology



#### Genetic studies for Alzheimer's Disease in Peru and Bolivia

Dr giuseppe tosto

Columbia University, New York, USA

#### **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

The frequency of Alzheimer's Disease and related dementias (ADRD) is projected to increase dramatically over the next few years. Hispanic individuals (genetically admixed of European, African and Native American ancestry) show a higher frequency of ADRD compared to non-admixed European populations. Yet, Hispanics are underrepresented in ADRD genetic studies and sample sizes are insufficient to robustly identify risk and protective genetic variants, especially if rare.

Recent reports have shown APOE-ε4's large effect for ADRD (OR>5) in Peruvians, even higher than European-descend populations and comparable of those reported in East Asians. Studies of indigenous and rural low-literacy populations report higher dementia rates than non-indigenous, attributed to low education levels and a higher prevalence of other risk factors, including diabetes, hypertension, alcohol abuse, obesity, cardiovascular disease etc. However, we observed low prevalence rates of MCI (8.30%) and dementia (1.22%) in Quechua people (Puno, South Peru). These rates are close to other extreme low ADRD rates observed in specific regions, including indigenous Bolivians, rural Amazonian population, rural Indian agrarian population, and a Cree native population in Manitoba.

Few studies tackled these heterogenous findings, including the potential protective effect of Native American ancestry on ADRD. To this end, in 2020 we have launched a pilot study ("GAPP": "Genetics of Alzheimer in Peruvian Populations" - NIH/NIA R56AG069118), recruiting Peruvian mestizos in Lima as well as Aymara and Quechua people in Puno and Arequipa. We successfully collected over 700 participants, phenotyped for dementia and cognitive impairment, in addition to several age-related risk and protective factors. This cohort led to several findings (in press or under publication). We have recently been funded for an even larger enrollment effort ("GLASS": Global Latino Sequencing Study - NIH/NIA U01AG081817) that will recruit additional 2,000 Peruvians and Bolivians across 10 different sites, and generate GWAS, whole-genome sequencing and blood biomarkers data.

#### **Keywords**

Alzheimer's Disease, health disparities, genetic epidemiology





#### Feasibility of screening for cognitive impairment among older persons and referral by community health workers in Mukono district, Uganda

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Background:** In Uganda, cognitive impairment in older persons aged ≥60 years is often undiagnosed due to inadequate appreciation of the condition compounded with limitations of trained human resource able to conduct appropriate cognitive evaluations. Use of Community Health Workers (CHWs) especially in hard-to-reach communities can be an important link for older persons to the health facilities where they can receive adequate evaluations and interventions for cognitive challenges. The aim of the study was to assess the feasibility of screening for cognitive impairment among older persons and referral by CHWs in Mukono district, Uganda.

**Methods:** This was a sequential explanatory mixed methods study. The CHWs received a one-day training on causes, signs and symptoms, and management of cognitive impairment and screened older persons ≥60 years for cognitive impairment using the Alzheimer's Disease scale 8 (AD8). We conducted Kappa statistic for agreement between the CHWs and RAs and compared raw scores of the CHWs to Experts scores using Bland Altman and pair plots and corresponding analyses.

**Results:** We collected data from 385 older persons. We involved 12 CHWs and 75% were females, majority were married (58.3%) with at least a secondary education (66.7%). There was an 88% agreement between RAs and CHWs in identifying cognitive impairment with the RAs identifying 49 (12.7%) older persons compared to 57 (14.8%) identified by CHWs. Of the 57 identified to have cognitive impairment by the CHWs, 94.7% were referred for care. The average difference between the score of the expert and that of the CHW was -0.042 with a 95% Cl of -1.335 to 1.252. Corresponding Bland Altman and pair plots showed high agreement between the measurements although CHWs scored higher values with increasing scores.

**Conclusion:** CHWs can be trained to identify and refer older persons with cognitive impairment in the communities.

#### **Keywords**

Mental State Examination, Mild Cognitive Impairment, Older persons Community Health Workers



### Systematic Assessment of Cognition at Preventive Home Visits; The HOS DEM study

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Aim:** 1) To investigate if systematic assessment of cognition at home visits identifies citizens with impaired cognition. 2) To gain knowledge on how this assessment is experienced by participants and their relatives.

**Method:** In a feasibility study we assessed cognition from 1/1 2022 to 1/31 2023 in three municipalities in Denmark. Assessments were completed with the validated Brief Assessment of Cognition Questionnaire, which includes seven questions to the participant and three questions to a relative (if the participant decided a relative should be invited). Participants were included and assessed at the well established Preventive Home Visits, that is offered to all citizens at the ages of 75, 80 and 82+ years. Participants with possible impaired cognition were motivated to consult their General Practitioner for further evaluation to facilitate further diagnostic evaluation, if relevant. Follow-up at General Practitioners and Memory Clinics will be investigated through registries in a later study. Experiences by participants and relatives were explored through interviews.

**Preliminary results:** Cognition were assessed in 898 participants of whom 14 % (125) had impaired cognition and 21 % (189) had slightly impaired cognition. Median age among participants were 80 years (range 64-102 years) and 55 % were women. Almost all participants invited a relative to the study, primarily spouse (46%) and a child (45%). Interviews were completed with 24 participants and 16 relatives, who represented different levels of cognition. Participants and relatives were positive about the systematic assessment of cognition, and it did not lead to worry. On the contrary, it facilitated awareness on symptoms of dementia and the importance of diagnosis. All results will be presented at the conference.

**Preliminary conclusion:** It is possible to identify people with impaired cognition through a systematic assessment at home visits, and the assessment increases awareness on one's own cognition and on dementia symptoms in general.

#### **Keywords**

Cognitive assessment, Early diagnosis, Dementia, Prevention



# The De-Sign Erasmus+ project: Dementia Raising Awareness seminars in Deaf communities and Adaptation of the first Cognitive Screening Test in Austrian and Greek Sign Language

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Introduction:** Supporting early detection encompasses public education programs and good access to information (Alzheimer's Disease International 2011). However, poor access to dementiarelated information in sign languages has been identified as a significant inequality for Deaf communities around the world, and to date, awareness of the early signs of dementia among them is very low.

**Aim:** The objectives focus on promoting the full participation and social inclusion of Deaf people by creating opportunities for equal access to dementia health services in Austria, Germany, Greece, and Italy by informing different groups of people involving Deaf individuals as well as their family members, health professionals and the public. Moreover, a second objective is to adapt the first Cognitive Screening Test, initially created by Atkinson et al. (2015), into the sign languages of Austria and Greece.

**Results:** This program is a group action between partners from Austria, Germany, Greece, and Italy who will: a) present the training materials for enriching knowledge about deafness and dementia as well as implementing dementia awareness seminars for the Deaf community, and b) introduce the Cognitive Screening Test in Austrian and Greek Sign Languages through a digital platform designed for this purpose.

**Discussion:** The final goal is to create an environment where Deaf people will have equal access to information about dementia and to services where dementia can be reliably diagnosed and treated.

#### **Keywords**

Dementia in the Deaf older adults, Cognitive screening in the Deaf



### EBC Rethinking Alzheimer's disease: Scaling up health systems' readiness

#### **Prof Giovanni Frisoni**

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

Alzheimer's disease (AD), the most common form of dementia, is a progressive and debilitating neurodegenerative condition which robs people of their memory, their independence, their relationships and, ultimately, their lives. It affects close to 7 million people in the European Union (EU) alone.

The detection and diagnosis of AD relies on a system that remains focused on the late stage of the disease, despite a better understanding of the disease progression. Clinical practice and healthcare systems' readiness to detect, diagnose and treat the disease effectively are still lagging. The use of biomarkers (cerebrospinal fluid tests (CSF) and positron emission tomography scans (PET)), which are central to a diagnostic assessment for people with AD symptoms, as well as relevant diagnostic facilities are under-utilised. PET imaging is expensive and of limited availability, and CSF sampling may be considered invasive.

The European Brain Council's 'Rethinking Alzheimer's disease: Detection and diagnosis' White Paper has looked at the barriers to early diagnosis and how the healthcare systems infrastructure for detection and diagnosis of AD need to be transformed in order for people with AD to benefit from innovative solutions once they become approved for use. The Rethinking Schizophrenia project falls under the *Rethinking the management of brain disorders series*, research-driven projects offering policy recommendations to make tangible changes with the aim to improve the lives of people living with brain disorders, neurological and mental alike, across Europe. More details about the outcomes of the Rethinking Alzheimer's disease project can be found in *this article*.

#### **Keywords**

Alzheimer's disease, Detection, Diagnosis, Preparedness, Biomarkers



### The acceptability and feasibility of a community dementia screening programme in rural Kenya: DEM-SKY

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Background:** Within Kenya, dementia is commonly under-recognised and under-diagnosed. As a result, many people living with dementia do so without any formal support. The DEM-SKY project seeks to address this gap by implementing a dementia screening program in Kenya using Community Health Volunteers (CHVs). The aim of this study is to describe the projects achievements, alongside implementation outcomes.

**Methods:** Older adults (aged 60 years and older) were opportunistically screened for dementia using the Brief Community Screening Instrument for Dementia (CSID) within Makueni County, Kenya. We captured perceived accuracy and acceptability of the intervention, alongside behavioural intention outcomes. Quantitative outcomes were complemented by qualitative interviews.

**Results:** Of the 3,546 older adults who were screened for dementia, 652 screened positive (PR = 0.18, 95%Cls 0.17 to 0.20). The majority of older adults felt that the screening met their approval (98.6%), liked it (99.4%) and welcomed it (99.1%). Many also felt very confident about the accuracy of the dementia screening programme (96.0%). Just over a third of participants said they would speak to a doctor about the screening outcome. Those who screened positive were 27 times more likely to have the intention to speak to a doctor and were 15 times more likely to seek a diagnosis during the study period.

**Conclusion:** The findings highlight that the community dementia screening programme is well received in rural Kenya. The study demonstrates that screening can be a simple way at promote people with dementia symptoms to seek a formal diagnosis in a rural Kenyan setting. There is the potential for similar CHV-led dementia screening programmes to be delivered in other Low- and Middle-Income Countries.

#### **Keywords**

screening, LMIC, kenya, implementation, acceptability, feasibility, diagnosis



### Under-diagnosis of Dementia in Nursing Home Residents: A Scoping Review

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Background:** The prevalence of dementia is increasing worldwide, and it is identified as a significant public health issue by WHO. Timely diagnosis of dementia is important, both in community and residential aged care facilities(RACF).

**Objective:** To investigate the extent of dementia under-diagnosis amongst residents of RACF, identify the factors associated with dementia under-diagnosis, and its consequences, and explore any interventions implemented, focused on improving the rate of diagnosis.

**Methods:** A scoping review based on Arksey, and O'Malley's scoping review framework was conducted within the PRISMA extension for Scoping Reviews (PRISMA-ScR). Relevant health-focused databases were searched for studies published in English since 2010. Search strategy was developed in collaboration with the supervisors and librarian.

**Results:** 545 studies were identified for screening the titles and abstracts. 20 studies were included for full-text review by two independent reviewers. Six studies were included for data extraction.

Undiagnosed dementia was in the range of 30-70%. Not all studies explored the factors associated with underdiagnosis. Health consequences were not explored in these studies but commented on residents missing dementia-catered care and low rates of dementia treatment. None of the studies undertook interventions to improve the rate of diagnosis.

**Discussion:** Underdiagnosis is a universal issue, and has an impact on health outcomes and quality of life. This scoping review looked at relatively large studies, which have confirmed the prevalence of underdiagnosis. This is a significant cohort that misses out on dementia-centred care. Despite being a well-known issue, interventions focused on improving this were not identified.

#### **Keywords**

Missed, undetected, unrecognized, under-recognized dementia, diagnosis, nursing homes, residential care, long-term care, aged care homes, permanent care facilities.



#### **S1-001**

### The World-Wide FINGERS Global Strategy for Precision Prevention of Dementia and Alzheimer's Disease

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Background:** Prevention is key to halt the growing numbers of Alzheimer's disease (AD) and dementia cases globally. Precision Prevention – the right intervention for the right person at the right time– is a recent endeavour in the AD field, requiring integration of multidimensional data from large and representative populations, to identify defined clusters and phenotypes, for early and accurate detection of prevention potential.

**Aims:** The World-Wide FINGERS (WW-FINGERS) network of multidomain trials for risk reduction and prevention of dementia includes 60+ countries. The network aims to adapt and test the original model from the FINGER trial – Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability – which showed that a multidomain intervention can benefit cognition in older adults at-risk of dementia.

**Methods:** The FINGERS Brain Health Institute established the WW-FINGERS Global Scientific Coordinating Center (GSCC), supporting prospective harmonization of the network trials, and coordinating international collaboration, via International Working Groups (IWGs) focused on prominent features of the trials. The GSCC multidisciplinary team supports establishment of FINGER-like protocols and data analysis within the network.

**Results:** The WW-FINGERS network has completed 13 trials, while 16 are ongoing, accounting for 18000+ participants. Trial Harmonization Guidelines have been compiled, to support prospective data harmonization. The GSCC is coordinating two IWGs – Cognitive Outcomes, Fluid Biomarkers – which are working to optimize methodology and joint analysis. Additional IWGs are planned. As new drugs have been approved for AD, the GSCC is developing infrastructure and resources for multidomain interventions combining pharmacological and non-pharmacological components. Collaborations with international stakeholders (e.g., Alzheimer's Disease International, Alzheimer's Disease Data Initiative), are ongoing to maximize outreach and enable data sharing.

**Conclusion:** The WW-FINGERS global collaboration is enabling scalability and evolution of the FINGER model, and prospective harmonization of multidomain trials, establishing the base for a Precision Prevention approach in AD and dementia.

#### **Keywords**

Precision Prevention, Risk Reduction, Dementia, Alzheimer's disease, Word-Wide-FINGERS, FINGERS, multidomain intervention, data harmonization, global collaboration



#### S1-002

### How Public Involvement Contributes to Effective Research on Prevention of Alzheimer's disease and Dementia.

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#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

**Background:** early detection, prevention and treatment of Alzheimer's disease (AD) and other pathologies causing dementia are growing efforts, leveraging on positive results of trials, novel tools for early diagnosis, and digital solutions supporting risk reduction. Such shift towards asymptomatic atrisk or early symptomatic stages can benefit from including the perspective of citizens through Public Involvement (PI).

**Aims:** Alzheimer Europe (AE) aimed to establish Advisory Boards (ABs) to conduct PI within multinational European projects on multidomain preventive interventions, including projects testing digital solutions enabling risk assessment, intervention delivery, and monitoring of adherence and efficacy. ABs are being established also for projects including blood-based markers reflecting brain pathology. PI aims to explore and include in these projects the perspectives of people affected by or with an interest in AD and brain health.

**Methods:** ABs have been set-up by AE in collaboration with clinical research teams, across several projects, including EU-FINGERS, LETHE, and Multi-MeMo. The ABs include lay people who are at different stages across the AD continuum (e.g., asymptomatic at-risk, Subjective Cognitive Decline, Mild Cognitive Impairment, early dementia) or carers for people living with dementia. The AB members are from different countries, they meet regularly, providing ongoing feedback and advice to the research teams. Synergy across the different ABs is enabled by AE, leveraging the interrelated aims of the projects, and includes also joint ABs meetings.

**Results:** We will report on the discussions and lessons learned on how to organise international ABs involving people at different stages across the AD continuum, and how to work in online settings. We will also summarise key outcomes of the discussions that took place so far, and the value of this work for the respective projects.

**Conclusion:** PI on AD prevention supports effective research, and proper approach towards ethical and societal issues related to such research.

#### **Keywords**

Public involvement, Brain health, Alzheimer's disease, Advisory Board, Prevention



#### S1-003

### LATam Fingers-Dominican Republic: findings from the baseline study interventions

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

LatAm-Fingers is a Latin-American Initiative, to develop a join protocol of regional intervention for the prevention of cognitive impairment and dementia, harmonizing and comparing data. The main objective is to built evidence in this population on the preventive interventions in groups at risks of cognitive deterioration. This initiative is based on the original Fingers and US Pointer protocols.

14 countries in Latino América are part of LatAm-Fingers: Argentina, Brazil, Bolivia, Chile, Colombia, Costa Rica, Cuba, Ecuador, México, Paraguay, Perú, Puerto Rico, Dominican Republic, and Uruguay. This Project is part of the World-Wide Fingers and Will follow its politics of the synergistic use of data, which will create a unique opportunity for the rapid dissemination and implementation of the knowledge obtained

**Aims:** This protocol is the first of a multi domains interventions coordinated in all Latin-America, as such, this is a pilot intervention of one year duration, (extended to a second year), with two main objectives:

- To demonstrate the viability of the project and the methods homogenization in all countries
- To built up data on the efficacy of the intervention

**Methods:** The multidomain lifestyle intervention model used in the original Fingers Study is tested in these populations and settings. We follow the same methods in all 14 centers. In the Dominican Republic we are testing this model in 100 participants from 60-77 years, the core of the trial method is harmonized and similar clinical outcomes are made to ensure comparability of findings, local adaptations implemented to account for cultural differences and facilitate adherence to the interventions.

Results: We are still analyzing data for this cohort which will be ready at the time of the conference.

**Conclusions:** Will show the results of the baseline interventions in Dominican Republic and show the cultural adaptations made for the implementation of the study.

#### **Keywords**

Dementia, risk factors, prevention



### Comparison of macro-structural narratives between Mild Cognitive Impairment and healthy ageing

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#### **Topic**

**Dementia research and innovation:** Younger onset, Mild Cognitive Impairment (MCI) and mild dementia

#### **Abstract**

**Background:** Timely detection of mild cognitive impairment (MCI) in older adults is a crucial prerequisite for early intervention, yet early identification of high-risk populations for cognitive impairment remains challenging. The MSSG (Main Concept, Sequencing, and Story Grammar) is a multi-level analytical approach that has shown potential utility through large sample studies in individuals with aphasia and traumatic brain injury. However, it has not yet been explored in older adults with cognitive impairment.

**Aims:** The study explored narrative linguistic markers of MCI through comparing the macrolinguistic narrative discourse between mild cognitive impairment and healthy ageing.

**Method:** Twenty-seven individuals with MCI and twenty-seven cognitively healthy older adults participated in a story recall task of "the Cowherd and the Weaver Girl". Transcripts of the produced narratives were encoded, and five macrolinguistic variables were compared: main concepts composite, sequencing, essential story grammar components, total episodic components, and episodic complexity. Binary logistic regression and receiver operating characteristic curve analysis were used for group differentiation.

**Results:** MCI group scored significantly lower than the healthy control group on all variables (p<0.01 or p<0.05). Differences were also practically significant with medium to large effect sizes (Cohen's d=0.61-0.82). Main concepts composite (OR=1.518, 95%Cl=1.071-2.150, p=0.019), total episodic components (OR=0.187, 95%Cl=0.036-0.985, p=0.048) and episodic complexity (OR=3.639, 95%Cl=1.056-12.544, p=0.041) effectively predicted group classification with an AUC of 0.817 (95%Cl=0.706-0.928, p<0.001).

**Conclusions:** This study shows that macrostructural narrative is a useful tool for revealing declined language abilities in participants with MCI. These discourse measures can serve as potential linguistic markers to help differentiate between MCI and healthy aging, thus facilitating early diagnosis and intervention for mild cognitive impairment.

#### **Keywords**

mild cognitive impairment, narrative discourse, macrostructural features, main concept analysis, linguistic marker



# Interdisciplinary psychosocial sensory interventions for persons living with moderate to advanced stage dementia in the long-term care setting in Singapore

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#### **Topic**

Dementia research and innovation: Mid-to-late stages of dementia

#### **Abstract**

**Introduction:** With an increasing number of people living with moderate to advanced dementia, there is a need to develop holistic interventions to support them to live with dignity. As persons living with moderate to advanced dementia often experience sensory and communication barriers, multisensory approaches have demonstrated potential to enhance the behavioral, emotional, and cognitive capacities for meaningful engagement.

This presentation illustrates how sensory approaches can enhance the quality of life and engagement for nursing home residents living with moderate to advanced dementia and its impact on care partners and next-of-kins.

**Methods:** Extending beyond the principles from Namaste Care, social workers and art and music therapists jointly used multisensory approaches to address the biopsychosocial spiritual needs of nursing home residents living with moderate to advanced dementia and next-of-kins.

- 1. Loving Touch Programme Through sensory stimulation, shared activity and environmental modifications, it incorporates psychosocial and spiritual sensory elements to enhance interactions among residents, others and surroundings.
- 2. HERE Together Sensory Engagements, Stories and Celebrations Stands for Here in the present Embracing connections, Reconnecting with our identities and Experiencing life Together. Through curated meaningful materials, it seeks to affirm residents' personhood and create new memories.

Residents' responses and well-being scores were recorded using a modified MATADOC scale and the Bradford Well-being Profile respectively. Qualitative feedback were also gathered post sessions.

**Results:** Preliminary findings indicated an increased in residents' engagement levels and deepened understanding of residents' capacities and preferences, thereby enhancing routine care. Care partners also reported feeling inspired to continue connecting with residents.

**Conclusion:** Sensory approaches bring out capacities of persons living with moderate to advanced dementia through various opportunities for responses within a single activity. With the flexibility to tailor experiences to their abilities, sensory approaches fostered deeper connections and promoted well-being and quality of life.

#### **Keywords**

Mid-to-late stages of dementia, Psychosocial interventions, Dementia therapies



#### **I1-003**

# Maintenance effects of short-period isodose intensive expressive arts program in the elderly with mild cognitive impairment: A pilot study

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#### **Topic**

**Dementia research and innovation:** Younger onset, Mild Cognitive Impairment (MCI) and mild dementia

#### **Abstract**

**Aims** To assess the maintenance effectiveness of a short-period isodose intensive creative expressive arts-based storytelling (SPI-CrEAS) program in older patients with mild cognitive impairment.

**Method** This two-arm, single-blinded, pilot, randomised controlled trial was conducted at the Geriatric Medicine Centre in Fujian Province. Overall, 38 participants were included in this study. The participants had previously completed a 24-week creative expression arts-based storytelling (CrEAS) project. Eligible participants were randomly assigned to receive maintenance CrEAS program twice weekly for an additional 12 weeks (SPI-CrEAS) or complete their daily activities (control group). Cognitive function was measured using a neuropsychological battery. All variables were measured at 12-week and 36-week follow-ups.

**Results** At the 12-week follow-up, significant improvements in verbal function (Verbal Fluency Test, P=0.021) were observed in the SPI-CrEAS group, as compared with the control group. The cognitive benefits of SPI-CrEAS were sustained with twice-weekly training for 3 months, lasting for up to 9 months.

**Conclusion** The initial cognitive improvement following CrEAS was sustained at follow-up and boosted by SPI-CrEAS.

#### **Keywords**

Mild cognitive impairment, Expressive arts, Maintenance, WeChat applet



#### **I1-004**

### Childhood dementia: the collective impact and opportunities for intervention

**Dr Kristina Elvidge**<sup>1</sup>, Prof John Christodoulou<sup>2,3</sup>, Prof Michelle A. Farrar<sup>4,5</sup>, Mr Dominic Tilden<sup>6</sup>, Ms Megan Maack<sup>1</sup>, Dr Nicholas J.C. Smith<sup>7,8</sup>

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#### **Topic**

**Dementia research and innovation:** Less common dementias and syndromes (including Down Syndrome and childhood dementia)

#### **Abstract**

Childhood dementia is a devastating and under-recognised group of conditions with a high level of unmet need. Typically monogenic in origin, this collective of neurodegenerative conditions are defined by a progressive impairment of neurocognitive function, presenting in infancy, childhood or adolescence.

We undertook a scoping review and burden of illness study to understand the spectrum of childhood dementia conditions and their impact. A literature review identified conditions that met the case definition and an expert clinical working group reviewed and ratified inclusion. Epidemiological data were extracted from published literature and collective incidence, prevalence and life expectancy were modelled.

Over 145 individual genetic conditions were identified that can be consistently defined as childhood dementia with the largest proportion of births belonging to the lysosomal disease and mitochondrial disease categories. Collectively the incidence is surprisingly high at 1 in 2,900 births and the life expectancy is low, a median of just 9 years of age. A relational database of the childhood dementia disorders has been created and will be continually updated as new disorders are identified (https://knowledgebase.childhooddementia.org/).

This scoping review highlights the importance of grouping these conditions as a phenotypic syndrome, rather than individually rare conditions, in keeping with the approach to adult dementia. Opportunities exist to address overlapping disease mechanisms and utilise therapeutic platforms for multiple childhood dementia conditions to tap into significant economies of scale. Collaboration with adult dementia researchers on common disease attributes is also expected to be mutually beneficial.

By unifying these conditions, we have highlighted the many unmet needs of this significantly disadvantaged group of children and young people and the data presented here will enable advocacy for systemic change in treatment, care, and support for them and their families.

#### **Keywords**

childhood dementia, genetics, neurodegeneration, rare neurological diseases, childhood-onset dementia



#### **I1-005**

## The State of Advance Directives for People with Dementia in Japan: A Survey of Family Caregivers in the Middle to Late Stage of Dementia

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#### **Topic**

Dementia research and innovation: Mid-to-late stages of dementia

#### **Abstract**

Purpose: To understand the status of advance directives for people with dementia(PWD) in Japan.

**Method:** A questionnaire survey of family caregivers of PWD in the middle to late stages of dementia was conducted in Japan (November 2022 to January 2023).

**Survey content:** Basic attributes of respondents, preparation status and content of advance directives for PWD, timing of discussions, and willingness of family members to continue caring for PWD.

**Ethical Considerations:** This study was conducted after review by the Ethics Committee of the corporation. This survey was subsidized by the FY2022 Subsidy for Promotion of Health Services for the Elderly.

Results: Responses from 699 family caregivers were obtained.

Family members had never discussed advance directives with PWD (52.4%), discussed them before the diagnosis (26.6%), and discussed them after the diagnosis (16.9%).

The timing of discussion was before dementia (57.7%), in the early stages of dementia (35.3%), when the family thinks about it (24.5%), and even in the middle to late stages of dementia when their intentions can be ascertained (21.5%).

The topics to be discussed were: people and places they wanted to spend their final days (62.9%), medical care they wanted to receive at the end of life (57.1%), wishes for daily life care (55.8%), places they wanted to receive end-of-life care (47.6%), property (40.2%), and funeral rites (35.2%).

**Discussion:** Those prepared as advance directives were 26.6%, and more than half of them had never discussed it. On the other hand, 21.2% indicated that it was possible to ascertain the person's wishes even in the middle to late stages of dementia. It is necessary not to give up because the person's wishes are not being heard. Education on advance directives has only just begun in Japan, and needs to be expanded along with the spread of dementia knowledge.

#### **Keywords**

Family Caregivers, Carers Support, middle to late stages of dementia



#### **Dementia Awareness: The Power of Social Media Influence**

Ms Sradha Sudarsanan, Mr Hugh O'Donoghue, Ms Niamh Burke

The Alzheimer Society of Ireland, Dublin, Ireland

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

As social media has become an intrinsic part of our lives, social media influence - a marketing term that describes a person's ability to affect other people's thinking in a social online community - has heightened. People are turning to their favourite Tik Tok stars and Instagram personalities for advice and guidance. Many social media influencers have access to huge audiences; the more influence an individual has, the more they shape people's attitudes and behaviours. However, when it comes to driving disease awareness - and sharing personal stories to increase awareness - just how much influence do they have? And what happens when a healthcare service-provider features an influencer voice in a campaign?

As the prevalence of dementia continues to grow globally, so does the urgent need to increase awareness and understanding of the condition. In Ireland, there are 11,000 new cases of dementia yearly alone. The Alzheimer Society of Ireland, the leading dementia-specific service provider in Ireland, recently worked with Irish model and social media influencer Joanna Cooper on their annual 'Denim Day for Dementia' fundraiser. Joanna has a personal connection to the condition; her mother Terri lives with Young-Onset Dementia.

The powerful and successful campaign sparked a huge response across social media, with Joanna opening the conversation around dementia and encouraging others to talk openly and honestly about it. In this presentation, we will discuss this further; exploring the role social media influence plays in driving awareness around dementia and how social media influencers can help to amplify the voice of dementia charities.

#### **Keywords**

social media, dementia awareness



# Conscious-creating metaphors and uplifting narratives as gamechangers to support human flourishing. Experiences from the field of dementia in Denmark.

#### Mrs Vibeke Drevsen Bach

Energy2work, Copenhagen, Denmark

#### **Topic**

**Dementia awareness:** Attitudes, awareness and stigma

#### **Abstract**

**Introduction:** Clinical diagnostic language is not designed to create uplifting images or a high degree of understanding, empathy and compassion towards persons with cognitive or developmental disorders or challenges. Nor does it give relatives supportive ideas on how to understand and best support and empower loved ones.

Could well-chosen metaphors and inspirational narratives teach, inspire, support, and empower both individuals with cognitive or developmental disorders, families, and whole societies - all around the globe?

**Aim:** To make visible to the world how new angles upon worldwide, challenging diagnoses has untapped potential in terms of disseminating those in new inspirational, conscious creating ways and promoting the likelihood of human flourishing.

**Materials And Methods:** 20 years of developmental work translating Tom Kitwoods dementia care theory in to new language, teaching and learning methods, testing and disseminating information on the phenomenon of dementia to more than 100.000 people from all over the dementia field in Denmark and the Nordic countries, demonstrates that well thought out imaging, awareness-raising metaphors and supporting narratives have unimaginable potential in terms of promoting a deep and much more heartfelt understanding of life for people with cognitive impairments, their challenges, potentials and the possibilities for human flourishing.

**Results:** Municipalities, families, associations, politicians, leaders, educational institutions, etc., draw upon this developmental work in their own strategies or attempts to uplift public consciousness and bring forth a radical new mindset around dementia.

**Conclusions:** According to responses from the vast majority, people radically change their perspective upon the diagnose dementia, change their view of persons living with dementia and their understanding of the vast and unused potential for human flourishing. Staff and families become empowered, creative, empathetic, imaginative, and supportive in ways that benefit all and everyone. Here is a huge potential that should be further explored and investigated in other areas.

#### **Keywords**

Diagnose perspectives, translating methods, public dissemination and teaching methods, metaphorical language, heart-based intentions, empowering methods, mind-set, cultural change, human flourishing,



### Cognition, gender and dementia literacy are associated with increased modifiable dementia risk in rural and remote adults

Miss Laura Eliza Dodds<sup>1</sup>, Dr Kay Deckers<sup>2</sup>, Dr Celia Harris<sup>1</sup>, Dr Joyce Siette<sup>1</sup>

<sup>1</sup>MARCS Institute, Western Sydney University, Westmead, Australia. <sup>2</sup>Alzheimer Center Limburg, School for Mental Health and Neuroscience, Maastricht University, Maastricht, Netherlands

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aims:** Dementia is a major public health issue. Rural and remote older Australians are underrepresented in cognitive health and dementia research, despite encountering unique healthcare obstacles, exacerbating the need for specialised research. Our study aims to identify levels of modifiable dementia risk, awareness of dementia risk reduction, and factors associated with modifiable dementia risk in rural and remote older Australians.

**Methods:** 207 adults aged >55 years from rural areas of Australia completed a cross-sectional online survey and a telephone-based cognitive assessment. Demographic data, awareness of dementia risk reduction, modifiable dementia risk (Lifestyle for BRAin health score) and global cognition scores (Telephone Interview for Cognitive Status-Modified) were collected. Multiple linear regression analysis examined associations between demographic factors and modifiable dementia risk.

**Results:** Participants had a mean age of 68.7 [SD=6.6] years. Majority were female (68.6%), English-speaking (94.7%), living in low socioeconomic areas (61.3%). They had lived in a rural area for an average of 24.5 [SD=17.7] years. Level of modifiable dementia risk was low-medium (Mean=-1.5, [SD=2.2]) and cognition scores (Mean= 29.3, [SD=4.0]) were above age and education norms. Over 90% of participants believed that dementia risk is modifiable. Male sex ( $\beta$ =-.92, 95% CI:-1.63--.21), lower cognitive scores ( $\beta$ =-.67, 95% CI:-1.33--.002) and lower dementia literacy ( $\beta$ =-.11, 95% CI:-.20--.02) were significantly associated with higher levels of modifiable dementia risk.

**Conclusion:** These findings highlight the role of demographic factors in modifiable dementia risk among rural communities and emphasises the need for targeted strategies to lower dementia risk, and enhance knowledge of risk factors and cognitive health in rural and remote individuals.

#### **Keywords**

Dementia, Risk factors, Lifestyle, Cognition



### How theatre as art and public forum can foster dementia awareness.

#### **Ms Mary Crescenzo**

AlzAuthors, Redmond, WA, USA. Dementia Map, Portland, OR, USA

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Theatre can foster dementia awareness, as an avenue for the public, including people living with dementia and carers, to examine their attitudes, prejudices and stigma about dementia. At the New York debut of Planet A, a play about the inner world of dementia, as the playwright, I realized, from the sobs that I heard in the darkened theater at the play's conslusion, that people needed a safe space to release their feelings, ask questions, and comment on what they witnessed. Since then, the play is always followed by an audience Q&A/talk-back with a representative from a dementia-friendly support organization, the actors and playwright, and a writing response session.

Planet A began its evolution years before in the mid-nineties. As an arts strategist/practitioner working with persons living with dementia, I developed arts engagement methods utilizing visual art, music, movement/dance, poetry/storytelling to connect and communicating with the people I served in various care communities. When I drove home after work, I often found myself in tears in response to conditions that I observed and the range of attitudes of staff and administrators towards the residents. Each evening, to process my feelings, I began to write persona poems in the voices of the residents, from observation, imagination, and from random yet profound statements spoken by residents. These persona poems developed into Planet A, my monologue-based play.

Through theatre and other forms of arts engagement we can continue to illustrate, amidst the good, the bad and the ugly of this condition, that people with dementia must be afforded the dignity they deserve. Through theatre as public forum we can discover that people living with dementia are not so different than ourselves as we may presume. Specific monologues from Planet A will be included as part of this presentation.

#### **Keywords**

art, theatre, theater, public, forum, dementia, awareness, carers, dignity, stories, engagement, poetry, Alzheimer's, playwright, monologues, awareness, stigma, attitudes, storytelling



### Intergenerational co-design of a serious game to raise dementia awareness for children

**Prof Christine Brown Wilson**, Dr Sonya Clarke, Miss Stephanie Craig, Dr Patrick Stark, Dr Gillian Carter, Dr Gary Mitchell

Queen's University Belfast, Belfast, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Dementia affects over 500 million people and almost half of the population knows someone living with dementia. Despite this, dementia is still poorly understood with people living with dementia identifying that individuals, including their families do not always understand their capabilities. The stigma associated with the condition can also leave people living with dementia feeling isolated within the community having a negative impact on their wellbeing. To address, these issues, the research team including people living with dementia co-design serious games to raise dementia awareness. Codesign methodology enables people living with dementia to be meaningfully involved in design processes by focusing on their abilities and expertise. In this project, codesign groups were held in three schools to initially identify what children(aged 9-10) thought they needed to know about dementia and what they wanted in a game. Think bubbles and drawings were used to enable the children to meaningfully express their thoughts and feelings about dementia. The final co-design event brought the children and people living with dementia together to compare their ideas and develop the final ideas for the game. The Kids Dementia Game is a collection of stories interspersed with quizzes and fun games to collect points. Fifty children from three schools tested the game and told us they liked the storytelling approach, learnt a lot about dementia and found the game easy to use. This game can be used in schools or within the family for children and adults to learn more about dementia together.

#### **Keywords**

dementia, awareness, intergenerational, co-design, children



## **Empowering Communities: Social Media's Role in Raising Awareness about Alzheimer's and Related Dementia**

Mr Carlos L Olivas III

Carepartner/ Volunteer Alzheimer's Advocate, Sacramento, USA

#### **Topic**

Dementia awareness: Development, growth and the role of Alzheimer and dementia associations

#### **Abstract**

In our digitally connected world, this narrative champions the pivotal role of social media in combating the escalating challenge of Alzheimer's and related dementia. We explore the profound impact of platforms like Facebook, Twitter, and Instagram in spreading awareness and education about these conditions. Social media becomes a dynamic space where individuals, care partners, and professionals converge, sharing personal stories and expert insights.

Social media platforms serve as vibrant hubs where communities unite, breaking barriers through compelling narratives, graphics, and videos. Care partners play a crucial part in initiating discussions, offering valuable insights into the daily challenges faced. Through thoughtfully crafted content, these platforms debunk myths, highlight nuances, and stress the importance of early detection and care.

Education and support flourish within the digital realm. Care partners and healthcare professionals exchange resources, coping strategies, and the latest research findings. Online support groups provide safe havens, fostering connections and solace. Live sessions, webinars, and podcasts, led by experts, empower caregivers with knowledge and confidence, guiding them through the complexities of the care partner role.

Moreover, social media amplifies fundraising and research initiatives. Crowdfunding campaigns for vital research, medical facilities, and support services gain unparalleled visibility. People worldwide contribute, forming a collective force to find a cure and supporting those affected.

**Conclusion:** In the face of the growing Alzheimer's crisis, social media emerges as a beacon of hope. By leveraging its influence, we create a global movement of compassion and understanding. Armed with knowledge and digital platforms, care partners drive change, fostering a future where awareness and empathy prevail. Together, we transform the digital sphere into a force for positive transformation, enhancing the lives of millions affected by Alzheimer's and related dementia.

#### **Keywords**

social media, awareness, advocacy, education, nuances, myths, barriers, inclusion, insight, care partner, growth, development, connections, influencer champion, diversity, transformation



### Airport Universal Design: Views from Us Living with Dementia

#### Ms Miki Sato

Dementia Envoy for Tokyo, Tokyo, Japan

#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

Dementia-friendly airports are designed in such a way that they can be universally used by just anyone.

It all started when a person in charge of airport universal design came to my lecture.

After having online interview on issues of public transportation, I was appointed to the airport universal design review committee as a first person living with dementia in Japan and a mother of my son with autism.

Together with people with other invisible disabilities, experts and airport staffs, we toured the airport and discussed findings of good and bad points. We gave lecture to airport staffs as part of the Hidden Disabilities Sunflower campaign, in addition.

Efforts are being made at airports across the country to set up "calm down, cool down spaces". On guide display, "dementia" was added to "developmental, intellectual and mental disorders based on my suggestion.

Such a small change could help us living with dementia feel at ease and people come to know it's possible to fly even if they receive diagnosis of dementia.

We hope for a society where no one need to give up traveling around the world.

#### **Keywords**

Universal design, inclusive design, airport, invisible disablities



# PARTICIPATION, Participation, participation...: What is your focus when you talk about social participation of people with dementia?

Prof Satoko Hotta<sup>1</sup>, Dr Hiroshige Matsumoto<sup>2</sup>, Dr Shuji Tsuda<sup>3</sup>

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#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

Many studies argue that social participation enhances wellbeing of people with dementia. One of the fundamental principles of the Basic Act on Dementia to Promote an Inclusive Society in Japan includes securing opportunities to participate in activities in all areas of society.

Despite the growing interest on the social participation of people with dementia globally, there is no agreement on its definition.

In December 2021, we conducted e-survey of family caregivers of people living at home with early-stage cognitive impairment in Japan with the focus on out-of-home activities, social interactions and participation in the community. In this survey, we categorized social participation into 3 groups based on Levasseur et al.'s taxonomy. (1) activities with others around but not including a specific activity with them (e.g. walking, shopping, and eating out); (2) activities in collaboration with others to reach a common goal (e.g. visiting friends' homes, peer meetings, and group exercises); and (3) activities helping others or contributing to the community (e.g. doing volunteer work and involving in community organization activities). Over 90% had engaged in at least one of these activities.

Through introducing some features based on attributes or conditions, we would like to discuss importance to identify specific definition of social participation and position in the taxonomy if we really try to keep people participating.

#### **Keywords**

social participation, social interaction



## 'Co-production and collaboration: Creating the Allied Health Professionals Dementia Framework for Wales together'

Mrs Laura Braithwaite Stuart<sup>1</sup>, Dr Natalie Elliott<sup>2</sup>

<sup>1</sup>Betsi Cadwaladr University Health Board, Wrexham, United Kingdom. <sup>2</sup>Cardiff and Vale University Health Board, Cardiff, United Kingdom

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

**Background:** Historically, people living with dementia in Wales have experienced inequitable access to person-centred rehabilitation provided by Allied Health Professionals (AHPs). The creation of a new workforce framework aimed to outline how AHPs can support people living with dementia and carers to live a life of quality. It was imperative that the framework was rooted in the lived experience of dementia.

**Methods:** From the outset, co-production underpinned the framework's development, alongside Appreciative Inquiry (Bouterie-Harmon et al. 2012) and evidence-informed practice (Miles & Loughlin, 2011). Aligned with best-practice recommendations for strategy development (WHO, 2022), evidence-gathering consisted of lived experience listening events, a scoping review of AHP interventions, and a national workforce survey. A steering group of people living with dementia, carers and practitioners guided development.

**Results:** Evidence-gathering identified four priority areas to continue transformation of dementia care, centred around: 1) increasing access to AHPs; 2) strengthening research for AHP interventions; 3) increasing meaningful co-production; and 4) developing leadership to drive transformation.

Robust co-production throughout resulted in positive outcomes for the framework, along with reported benefits for practitioners and people with lived experience involved.

**Conclusion:** The evidence-informed approach to developing the AHP Dementia Framework for Wales resulted in a national workforce framework combining the best available empirical evidence, together with expertise of people living with dementia, carers and the AHP workforce. Meaningful co-production throughout development not only facilitated a strategy fit for purpose, but also importantly reflected the way in which AHP service transformation should occur moving forwards.

Bouterie-Harmon, R., Fontaine, D., Plews-Ogan, M. and Williams, A. (2012) Achieving Transformational Change: Using Appreciative Inquiry for Strategic-Planning in a School of Nursing. Journal of Professional Nursing, 28(2), pp.119-124. Miles, A and Loughlin, M. (2011) Models in the balance: evidence-based medicine versus evidence-informed individualised care. Journal of Evaluation in Clinical Practice, 17, 531-536.

### **Keywords**

Allied Health Professionals, Dementia, Co-production, Lived experience, Strategy development



# The impact of a collaborative approach on the development and delivery of creative workshops for people living with younger onset dementia and their families: Reflections from the consultation team

Dr Alison Ward<sup>1</sup>, Mr Peter Middleton<sup>2</sup>, Mr George Rook<sup>2</sup>, Dr Gemma Collard-Stokes<sup>2</sup>, **Dr Clive Holmwood**<sup>2</sup>

<sup>1</sup>University of Northampton, Northampton, United Kingdom. <sup>2</sup>University of Derby, Derby, United Kingdom

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

A collaborative consultation group was established to support and inform the adaptation of an innovative approach to deliver creative arts workshops for people living with younger onset dementia and their family. The aim of the group was to provide insight on engaging and supporting people with younger onset dementia and their family to participate in the sessions. Members of the research and collaboration group reflect on the personal and project benefits this has brought.

Five members were recruited to the consultation group. This included two people with a diagnosis of younger onset dementia, a dance and movement expert and former family carer, an experienced drama therapist, and a specialist community dementia nurse. The group met regularly, online, throughout the lifespan of the project to provide their expertise to support the development and delivery of the project.

The research team gained through the rich discussions about the nuances of language, ways to support people living with younger onset dementia, and embracing ideas that supported the effective workshop's delivery. The consultation group members developed their knowledge on creative arts process, experienced 'delight and excitement' in being part of the project team and seeing changes occur based on their input, knowledge and experience.

The direction and success of this project was enhanced through the involvement of the collaboration group. Working with members from different arts Background:s and with those living with a diagnosis of dementia changed perspectives and brought about rich and challenging discussions which had positive impacts on the overall project.

#### **Keywords**

Collaboration, younger onset dementia, involvement, creative, arts





# Growing capacity of PPI contributors to affect change in the dementia research environment; Lessons learned from an Irish research knowledge exchange seminar

Dr Diane O'Doherty, Dr Laura O'Philbin, Ms Cíara O'Reilly

The Alzheimer Society of Ireland, Dublin, Ireland

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

The value of person public involvement (PPI) is well-established in health research. PPI improves the quality and relevance of research through active PPI contributor feedback and expertise.

In 2023, The Alzheimer Society of Ireland, in collaboration with Dementia Research Network Ireland, hosted a research knowledge exchange event. To ensure accessibility and optimal collaboration, an Expert Advisory Panel was set up consisting of a person with dementia, a family carer, an early career researcher and a collaborator from Dementia Research Network Ireland. Dementia Research Network Ireland (DRNI) is an interdisciplinary dementia and neurodegenerative research initiative. Contributors advised on the event agenda, timing, room configuration, and accessibility and highlighted important needs, including quiet space for people living with dementia.

Approximately 50 people attended the event, including people with dementia, carers, researchers and clinicians. We facilitated mixed small discussion groups who worked together to develop a list of barriers and solutions for the implementation of research into practice. This enabled active co-collaboration and co-creation of ideas. Findings from these sessions have been brought together in a formal report, which is available on The ASI website. In sharing this knowledge with the wider European community, we can continue to affect change and bring value and meaningful experiences to dementia research.

#### **Keywords**

PPI, person public involvement, dementia research, knowledge exchange,



# Community pláticas: Engaging Latino stakeholders to define community-driven dementia care research priorities

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<sup>1</sup>University of Texas Health Science Center at San Antonio, San Antonio, USA. <sup>2</sup>Alzheimer's Association, Laredo, USA

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

**Background:** and Aims: Latinos are at greater risk for dementia yet remain severely underrepresented in research about dementia and dementia care. South Texas, a region with limited health care infrastructure, represents several of the most impacted counties in the United States in dementia prevalence. Aligning research with the experiences of Latino stakeholders is a critical step in addressing their exclusion from research. A community-engaged study sought to identify dementia care research priorities among Latinos in South Texas.

**Methods:** A Steering Council (SC) of stakeholders including persons living with dementia, family caregivers, community health workers, and care professionals was established and engaged in the facilitation of culturally-specific engagement activities (pláticas) with Latino communities in South Texas. The SC and study team analyzed qualitative data collected during pláticas to develop a survey of research topics organized by four overarching themes: Awareness of dementia; Living with dementia; Caring for someone living with dementia; and Resources to support families impacted by dementia. Respondents were prompted to rank each research topic from 1 to 10 on level of importance (1 least importance-10 greatest importance). The survey was administered in English and Spanish to a wider network of stakeholders in South Texas.

**Results:** N=148 stakeholders completed the research prioritization survey. Within each theme, top priorities emerged: Raising awareness about dementia and brain health among Latinos (9.2), Finding ways the health care system can make it easier to get a timely diagnosis (9.4), Identifying non-pharmacological treatments for behavioral symptoms (9.3), and making sure families have information to plan their future care (9.2).

**Conclusion:** Findings from this study support the alignment of research with the needs of communities disproportionately impacted by dementia. The community-engaged approach ensured the perspectives and leadership of key stakeholders were represented throughout the study.

#### **Keywords**

priorities, community-engaged, latino, minoritized





### Dementia Comprehensive Care: the pioneering of the state of Rio Grande do Sul in Brazil

Mrs Thaíssa Araújo Bessa<sup>1</sup>, Prof Edson Leandro de Ávila Minozzo<sup>2</sup>, Dr Elaine Mateus<sup>3</sup>, Mrs Ana Karina Anduchuka<sup>4</sup>, Mrs Ana Lúcia Galbarino Amaral<sup>1</sup>, Mrs Gisleine Lima da Silva<sup>1</sup>, Miss Maria Eduarda Sobieski Costa<sup>1</sup>, **Mrs Júlia Jochims Schneider**<sup>1</sup>, Mr Luiz Carlos da Silva Duarte<sup>1</sup>, Mrs Vanessa Rossoni de Oliveira<sup>1</sup>

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

Brazilian publics health system is one of the largest public care system in the world. The importance of correct dementia diagnosis and adequate care of this condition have boosted the Brazilian Senate proposed a law project, in 2021. This iniciative goal is to establish the National Policy of Integral Care to dementia's people and their caregivers. Rio Grande do Sul State has appoved the Law No. 15,820, in March 2022, to establish the Policy Statment to Combat Alzheimer's Disease and other Dementias. In 2023, as an articulated action between the government, public authorities, universities, institutions focused on dementia and social control, the elaboration of the country's first State Plan for Integral Care in Dementia has began to be developed. This local orientation follows the World Health Organization's Global guidelines plan in the public health response to dementia. The Plan's management committee is made up of more than 30 governmental and non-governmental institutions. Rio Grande do Sul Health's Department State is coordinating the drafting project. The first step is to access the main people involved in this process: primary health care professionals, specialists from different institutions and universities, representatives of associations for dementia's people, such as the Brazilian Federation of Alzheimer's Associations, as well family and caregivers. The Plan has four essential points: early diagnosis, health education, care management and monitoring datas, and social participation. The actions includes awareness campaigns, qualification courses for professionals with differents degree's level in health care and long term care suport. At the same time, the implementation of a indicator as a mesuarement and the analisys of these datas are others goals of these process. The deadline for the writing step is December 2023.

#### **Keywords**

dementia, public health, health providers



## Advocating for Change: A State-Level Dementia Action Plan in Karnataka, India

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

Dementia India Alliance (DIA) is a non-profit, family carer-centered national organization in India dedicated to enhancing the lives of individuals living with dementia and their families With approximately 8.8 million Indians currently affected by dementia and projections indicating a staggering rise by 2036, the urgency to address this issue is paramount.

The DIA emphasizes the need for a comprehensive national dementia plan while recognizing the complexities of healthcare priorities in India. As a practical approach, advocating for state-level policies on dementia is proposed to address immediate challenges. In Karnataka, where an estimated 350,000 individuals are affected by dementia, a robust healthcare ecosystem and various government initiatives lay a solid foundation for dementia care.

Aligned with the World Health Organization's global action plan on the public health response to dementia recommendations, the DIA and NIMHANS collaborated to urge the Health Minister of Karnataka, Shri Dinesh Gundu Rao, resulting in the declaration of "Dementia as a public health priority" and the subsequent formulation of a 'Karnataka State Dementia Action Plan.' This ground-breaking step positions Karnataka as a pioneer in India, aligning with the global action plan on dementia and setting an example for other regions to follow.

This presentation will delve into the imperative for a multi-sectorial public health approach to address dementia comprehensively. The focus will be on the advocacy efforts that led to the announcement, strategies, partnerships, and steps taken by DIA and stakeholders to drive policy changes at the state level, making Karnataka a leader in the mission to enhance the lives of those affected by dementia and their families.

#### **Keywords**

Global action plan on dementia, national plan, public health priority, multisectoral, Dementia India Alliance





#### **Dementia in the Commonwealth**

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

A strategic objective of CommonAge is the promotion of health and wellbeing among the populations of the 56 countries of the Commonwealth. Since its launch in 2013, CommonAge has been demonstrating, through evidence, issues relating to ageing, and our first research report, "Ageing in the Commonwealth," was published in 2018. As a follow-on project, CommonAge now intends to publish a report on "Dementia in the Commonwealth." In 2024, the Commonwealth will mark 75 years since its formation in 1949. This report would be CommonAge's contribution to the celebration of this milestone. The opportunity and the dynamics of global health awareness, and increasing international focus on dementia, combine to make 2024 an ideal year for CommonAge to present such a report designed to attract Commonwealth wide attention.

More than 55 million people have dementia worldwide, over 60% of whom live in low-and middle-income countries. Every year, there are nearly 10 million new cases. By 2050, 153 million people are expected to be living with dementia unless countries address risk factors. Dementia cases will rise in every country, with the smallest estimated increases in high-income Asia Pacific (53%) and western Europe (74%), and the largest growth in north Africa and the Middle East (367%) and eastern sub-Saharan Africa (357%).

In 2017 the WHO published its Global Action Plan calling on all member states to prepare National Dementia Plans (NDPs) by 2025. Progress has been slow and there is a need to stimulate greater priority to be given to meeting the challenge. The target date has been extended to 2030. Many Commonwealth countries need to be encouraged and supported to develop their NDPs. Our presentation will be designed to stimulate action by Commonwealth member states that have yet to develop their NDPs by offering evidence of best practice from across the Commonwealth.

#### **Keywords**

Dementia, Commonwealth, National. Development, Plans, Policy, Practice



### Strengthen services for people living with dementia in New Zealand

#### **Ms Catherine Hall**

Alzheimers New Zealand, Wellington, New Zealand

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

Dementia affects cognitive function that limits people with this health condition from expressing themselves, making their needs are often ignored or overlooked. People living with dementia should be respected and included in decisions about type of care and support they need.

Our research investigates the involvement of people living with dementia in the design and delivery of services for them, identities factors limiting and enhancing their contributions and whether actions have been taken because of their involvement.

Data collection includes a brief literature review, stocktake survey, and qualitative interviews with people living with dementia and service providers. Research is being completed in four stages of research design and ethics review, data collection, data analysis, and reporting. An advisory group representing people living with dementia, care partners, and researchers is established to guide the research.

We will share a presentation on how the involvement of people living with dementia in the design and delivery of support will not only provide them with access to the highest attainable standard of health care, but also will maintain their rights to make decisions that are important for them to live their best possible lives.

We will also share recommendations that can be beneficial in improving health services and reducing disparities and inequities experienced by some people living with dementia in New Zealand.

#### **Keywords**

Engaging people living with dementia, design, care and support.



# Strengths and shortcomings of public policies and support services for older persons with dementia in the GCC Arab region

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

In a world of ageing populations, persons living with -or at risk of- dementia have been among the most vulnerable population groups. Given their increased risk of comorbidities (namely diabetes, hypertension and depression), strengthening national responses to this particular population group has become a public health priority. In the context of global prioritization of healthy ageing within public policies in the health and social care sectors, the Decade of Healthy Aging, and the predicted aging surge in the GCC (Gulf Cooperation Council) Arab region, our study examines the extent to which the care and wellbeing of older persons living with dementia (PwD) has been safeguarded by governments, NGOs, and communities in GCC countries. It takes stock of existing support structures and policies that support PwDs and their caregivers, as well as non-governmental organizations' community-based support services, undertaking a policy review of relevant public policies and services, and insights from key informant interviews invested in this sector. This contribution aims at synthesizing the disparate efforts within the GCC region, with a view to identifying gaps, lessons learned and best practices that can enhance systems and policies which target older persons and their caregivers. Cross-fertilization of experiences across countries will support amplifying efforts and impacts in the region and beyond, highlighting common concerns and offering viable solutions.

#### **Keywords**

Older persons, dementia, ageing, Arab, services, policies, caregivers



# Acquired hearing loss: examining associations with other risk factors for insights, innovations, and inspirations in dementia risk reduction

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University of Tasmania, Hobart, Australia

#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** Global public health action is required to address the evidence-based and potentially modifiable risk factors for dementia, thus decreasing population risk by up to 40%. Based on population attributable fractions, hearing loss (HL) acquired in midlife contributes up to 8%, a significant proportion, of this risk. There may be associations between HL and other dementia risk factors, and this is important to know to implement effective, integrated, and innovative risk reduction initiatives.

**Method:** We gained insights from examining the prevalence of acquired HL in 1,274 adults aged ≥50 years and analysing the association between HL, social isolation (the size and support of social networks), anxiety, and depression. Participants were involved in the Island Study Linking Ageing and Neurodegenerative Disease (ISLAND), a 10-year program to promote health and reduce dementia risk through educational and community-based interventions.

**Results:** We used univariate multiple linear regression in cross-sectional data. Of 7,442 participants, 1,274 (17%) reported HL (corrected = 704, mean age = 70 yrs; uncorrected = 570, mean age = 66 years). Compared with no HL and corrected HL, uncorrected HL was a significant contributor to social isolation, anxiety, and depression, compounding the risk for dementia.

**Conclusions:** As social isolation and depression also are established risk factors for dementia and other chronic diseases, it is feasible that correcting HL acquired in midlife could yield a compounding risk reduction effect.

Similar relationships may exist between HL and hypertension, particularly for adults who smoke.

Needed actions are work with communities, healthcare professionals, and policy makers to co-design and implement effective and sustainable interprofessional interventions that recognise and address the associations between modifiable risk factors for dementia, including HL, social isolation, and depression.

#### **Keywords**

Hearing loss, social isolation, depression, codesign, integrated intervention





### Frequency of social isolation among older adults in Nepal

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Background:** Social isolation is a recently documented modifiable risk factor for dementia but little is known about its prevalence in low and middle-income countries (LMICs).1 Older adults in Nepal are increasingly at risk for social isolation given trends of adult child migration to other communities. The resultant social isolation increases risk for depression, psychological distress, and dementia2-3. This study aimed to estimate the prevalence of social isolation among older adults of Nepal and its associated factors.

**Methods:** A quantitative cross-sectional study in Dhulikhel municipality of Nepal. Two geographical regions within the city were randomly selected. Systematic random sampling was used for the selection of respondents. We employed the Lubben Social Network Scale (LSNS-18), a brief tool validated in LMIC, to quantify social isolation.4 Data were analyzed in Statistical Package for Social Sciences (SPSS) v25.

**Results:** More than half of respondents (52.3%) were age 60-70 years, 56.1% were male, 55.1 % were illiterate, and 59.8% were living in a nuclear family. More than one-third (37.4%) met the criteria for socially isolation. Social isolation associated with age (p=0.026), being a widow (p=0.002), living in a nuclear family (p= 0.001), and the presence of chronic diseases (p=0.014). Whereas, gender and education were not significantly associated with social isolation.

**Conclusion:** More than one third of older adults in this representative community met criteria for social isolation despite the family-based societal norms that are typical of Nepal. Addressing this issue may promote brain health among older adults. Further research is recommended to examine the cognitive health of this isolated population.

#### **Keywords**

Social isolation, risk, dementia



### Dementia Risk Awareness, Healthy Lifestyle, and Factors Influencing Motivation for Dementia Prevention in Middle-Aged And Older Adults

**Dr Seda Güney**, Mrs Özlem Çiçek Doğan, Miss Aylin Bakır, Miss Ayça Öztürk, Miss Tuğçe Oldaç Koç University, Istanbul, Turkey

#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** The aim of this study is to explore risk awareness and socio-demographic and healthy lifestyle factors that influence individuals' motivation to adopt dementia-preventive behaviors in a population aged 40 and over.

**Methods:** A descriptive and cross-sectional study was carried out between December 2022 and May 2023. A total of 384 people aged 40 years and older participated by using Qualtrics through social networks. Motivation to Change Lifestyle for Dementia Risk Reduction Scale (T-MOCHAD-10), Health Behavior Information Form, and Dementia Risk Awareness Form were used to collect the data.

**Results:** Most participants were under 65 years old (87.5%), predominantly female (76.6%), married (80.5%), and unemployed (55.5%). The study found that most participants were physically inactive (94.3%), although the prevalence of excessive alcohol consumption was remarkably low (1.0%). Smoking was significantly more common among people under 65 years of age, men and employed people (p<0.001, p=0.006, p<0.001). A significant majority (75.3%) of participants had limited knowledge about dementia, and almost half (49.7%) believed that preventing dementia was not possible. A small percentage of people (2.3%) were not aware of any risk factors, while 5.2% were aware of all risk factors. Motivation to change lifestyle in regards of age, employment status, physical activity, alcohol consumption, smoking, and adherence to the MIND diet showed no significant differences between groups. However, motivation was significantly higher in women (p<0.001). Participants with a college degree were less motivated to change lifestyles to reduce the risk of dementia (p=0.038). The results of multiple regression analysis showed that female gender and increased awareness of dementia risks were identified as two factors for motivation to change health behavior to prevent dementia (p < 0.001,  $\beta$  = 0.215,  $\beta$  = 0.217).

**Conclusion:** The study found that women and people who were aware of risk factors were more motivated to prevent dementia.

#### **Keywords**

Dementia risks, Awareness, Lifestyle, Motivation, Risk reduction



# Analysis of plasma gingipain K and R level and APOE genetic variants inpatients with Alzheimer's disease

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Background:** Alzheimer's disease (AD) is the most common progressive dementia disease in people over 65 years of age. The pathogenesis of this disease remains largely unknown. It is explained based on the following theories: amyloid cascade, inflammation, vascular, and infection hypothesis. Recently hypothesized that Porphyromonas gingivalis may be a unifying factor linking the different hypotheses related to AD pathogenesis. This pathogen, in the circulation or in the brain, may lead to AD-related pathologies including inflammation, endothelial barrier damage, BBB dysfunction, beta-amyloid production, and tau phosphorylation.

Porphyromonas gingivalis produces cysteine proteinases called gingipain K and gingipain R, which are virulence factors. The most important genetic factors responsible for AD include variants of the APOE. There are two polymorphisms in the APOE, which present three alleles: protective -  $\epsilon 2$ , neutral -  $\epsilon 3$ , and pathogenic -  $\epsilon 4$ . Subjects with the pathogenic allele have an increased susceptibility to AD, and an infectious agent increases it. So far, there is little information on the level of gingipain R and gingipain K in AD.

The aim of the study was to analyze plasma gingipain K and R concentration and APOE genetic variants in AD patients, control subjects related to AD cases (CR), and control subjects without a family history of AD (CU).

**Method:** The studies were conducted on 74 subjects (AD and controls). The APOE genotype was determined by real-time PCR. The gingipain K and R concentration was determined by the ELISA method.

**Results:** The highest concentration of gingipain K (p=0.0820) and R (p=0.0740) was found in AD compared to CR, and CU. However, the highest concentration of gingipain R was found in AD patients APOE  $\varepsilon$ 4 carriers (p=0.0701), and gingipain K in AD non-carriers of this allele.

Conclusion: It seems that both gingipains K and R may be involved in the pathogenesis of AD.

#### **Keywords**

Alzheimer's pathology, risk factors, gingipain, APOE



# Does motor decline can be a modifiable marker of clinical progression in subjective cognitive decline?: A national prospective cohort study

**Miss Ran An**, Prof Qiaoqin Wan Peking University, Beijing, China

#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aim:** Subjective cognitive decline (SCD) represents a crucial period for preventing the onset of mild cognitive impairment and dementia. While various motor functions have been linked to the clinical progression of SCD, findings are inconsistent and their independent and joint relationships remain unclear. This study aimed to elucidate the independent and joint associations between the clinical progression of SCD and various motor functions.

**Method:** We included 4,880 elderly participants from a national cohort and used Cox proportional hazard regression model and restricted cubic spline models to explore the longitudinal associations between motor functions (gait, strength, balance, and endurance) and clinical progression in SCD.

**Results:** During an average follow-up period of 4.5 years, 1239 participants with SCD experienced clinical progression. After adjusting for demographics, vascular burden, and body components, gait speed [hazard ratios (HRs)= 0.96, 95% confidence interval (CI) 0.93-0.98], grip strength (HRs=0.99, 95%CI 0.98-0.99), chair stand test (HRs=0.99, 95%CI 0.98-0.99), endurance limitation in jogging 1 kilometer (HRs=1.18, 95%CI 1.04-1.35) were significantly associated with risk of clinical progression. Among all participants, those characterized by poor upper- and lower-body strength, as well as those with slow pace combined with worse endurance, had the highest risk of cognitive impairment. Additionally, our analysis using restricted cubic splines revealed significant non-linear S-shaped associations between motor performance and the risk of clinical progression in SCD. Continuous measurements of gait speed, grip strength, and chair stand test were associated with cognitive impairment, with key change points identified at 0.71 meters/second, 29 kilograms, and 10.2 seconds, respectively.

**Conclusions:** Our study emphasizes the potential of gait speed, muscle strength, and endurance as non-cognitive indicators of clinical progression in SCD. Given that motor function is modifiable, interventions should be developed to enhance motor fitness in SCD individuals, reducing the risk of incident dementia.

#### **Keywords**

Subjective cognitive decline, Motor function, Gait speed, Strength, Endurance, Dose-response



### Changes in cognitive functioning in older adults with dementia due to lifestyle and psychological variables: A multivariate multiple regression model approach.

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All India Institute of Medical Sciences, New Delhi, India

#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aim:** This study aimed to understand the impact of lifestyle and psychological risk factors on cognitive functioning in older adults with Alzheimer's disease (AD) or Mild Cognitive Impairment (MCI).

**Methods:** 87 Indian patients with probable AD or MCI were included (mean age= 68.8 years, SD=9.7, males=64). A multivariate multiple linear regression model was developed using 7 response variables and 10 predictors. The beta-coefficients (β), respective Standard Error (SE), and p-values were estimated for each predictor separately. A p-value <0.05 was the threshold of statistical significance. RStudio (4.3.2) was used to build the model. Ethical clearance was obtained from the Ethics Committee, All India Institute of Medical Sciences, New Delhi (IEC-162/05.04.2019, RP-40/2019).

**Results:** When Trail Making Test-Part B score was selected as the response variable, intercept [β: 129.25 (56.59)] and dietary diversity [β: 14.47 (4.72)] were statistically significant. Digit Span-backwards score as the response variable yielded no significant predictor. With the Picture Naming Test scores as the response variable, intercept [β:104.32 (18.6)], depression [β: -2.01 (0.67)], and exposure to adverse experiences during childhood [β: 1.94 (0.91)] were significant. With Instrumental Activities of Daily Living for Elderly People scores as the response variable, dietary diversity was significant [β: -5.14 (1.79)]. Modified Taylor Complex Figure-delayed recall score as response variable, physical activity [β: 0.01 (0.00)] was significant. Addenbrooke's Cognitive Examination-III score as response variable yielded intercept [β: 46.12 (12.71)], care-partner burden [β: -0.33 (0.11)], dietary diversity [β: 2.84(1.06)], and physical activity [β: 0.01 (0.01)] as significant. Finally, with Clinical Dementia Rating as the response variable, intercept [β: 1.67 (0.51)], care-partner burden [β: 0.01 (0.01)], dietary diversity [β: -0.10 (0.04)], and sleep quality [β: -0.07 (0.03)] were significant.

**Conclusion:** Dietary diversity, physical exercise, and care-partner burden predicted scores on multiple cognitive assessments.

#### **Keywords**

Alzheimer's disease, Mild Cognitive Impairment, psychological risk factors, lifestyle, multivariate multiple regression model.



# **Correlation Analysis of Subjective Memory Complaints Across Different Populations**

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Shanghai Mental Health Center, ShangHai, China

#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Objective:** Subjective Memory Complaint (SMC) is a condition where individuals experience subjective memory decline, with or without objective memory impairment. SMC occurs at a high rate in both Normal Cognitive (NC) and Mild Cognitive Impairment (MCI) populations and is one of the risk factors for dementia. This study explores the influencing factors of individuals with SMC in the community among those with NC and MCI, aiming to provide favorable intervention measures and strategies for dementia prevention.

Methods: A cross-sectional study was conducted, surveying 957 residents in Shanghai communities regarding their subjective memory. Cognitive function was assessed using the Montreal Cognitive Assessment (MoCA), and anxiety and depression were evaluated using the Self-Rating Anxiety Scale (SAS) and the 15-item Geriatric Depression Scale (GDS-15). Sleep quality was assessed using the Pittsburgh Sleep Quality Index (PSQI), and the Epworth Sleepiness Scale (ESS) measured daytime sleepiness. ApoE genotype and biochemical markers were also tested. Based on inclusion criteria, 223 individuals with NC and 177 with MCI were included. Logistic regression analysis was used to identify factors related to SMC.

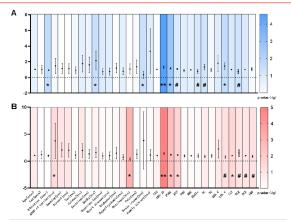


Fig. 1 Establishment of a univariate logistic regression model for SMC among different populations. (A) Establishment of a univariate logistic regression model for SMC among non-MCI populations. (B) Establishment of a univariate logistic regression model for SMC among MCI populations. (B) Establishment of a univariate logistic regression model for SMC among MCI populations. (B) = \$P.001, \*\* \$P.005, \*\*\* \$P.000, 1\*\* \$P.000, 1\*\* SAS = flee Self-Rating Anxiety Scale; GDS-15 = the 15-item Geriatric Depression Scale; PSOI = the Pittsburgh Sleep Quality Index; ESS = the Epworth Sleepiness Scale; FBG = flasting blood glucose; RBG = random blood glucose; HBA1c = glycosylated hemoglobin; TC = total cholesterol; TG = triglycerick; DL1-C = low density lipoprotein cholesterol; IIID-C = high density lipoprotein cholesterol; SIII-systemic immune-inflammation index; NLR = neutrophil-to-lymphocyte ratio; LMR = lymphocyte-to-monocyte ratio.

**Results:** In the NC group, the Logistic regression model showed that factors influencing SMC were

a history of brain injury (OR=0.059, 0.006-0.611, p=0.018), GDS-15 score (OR=1.306, 1.121-1.522, p=0.001), ESS score (OR=1.131, 1.018-1.256, p=0.022) and Neutrophil-to-Lymphocyte Ratio (NLR) (OR=0.531, 0.329-0.857, p=0.010). In the MCI group, factors influencing SMC were ApoE e4 carriage (OR=3.812, 1.063-13.671, p=0.040), GDS-15 score (OR=1.408, 1.192-1.663, p<0.001) and dizziness (OR=2.497, 1.024-6.089, p=0.044) (Figures 1 and 2).

**Conclusion:** Depression is a risk factor for subjective memory complaints in both NC and MCI populations. In the NC group, a history of head injury and daytime sleepiness may be risk factors for SMC, while NLR may be a protective factor. In the MCI group, ApoE e4 carriage and dizziness are risk factors for SMC.

#### **Keywords**

elderly, subjective memory complaints, mild cognitive impairment, influencing factor



# Lifestyle, brain damage and dementia risk: Findings from studies with the Lifestyle for Brain Health index

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Background:** From a public health perspective, those at increased risk of dementia should be identified and informed based on readily available risk factors that are truly amenable to change. The Lifestyle for Brain Health (LIBRA) index was developed to quantify an individual's 'room for improvement' and has been extensively validated in different cohorts and against different outcomes.

**Method:** Following a systematic review and Delphi expert study in 2015, twelve modifiable dementia risk and protective factors were included which can be targeted by lifestyle interventions and primary prevention strategies: physical inactivity, smoking, alcohol use, cognitive activity, Mediterranean diet, depression, hypertension, obesity, diabetes, hypercholesterolemia, coronary heart disease, renal disease. Weights based on each factor's relative risk are summed up in a total score, with higher scores indicating a worse brain-healthy lifestyle.

**Results:** In epidemiological studies, a worse brain-healthy lifestyle summarized by LIBRA is associated with a higher risk for cognitive decline and dementia in the general population, more brain atrophy, more white matter damage, a higher brain age and worse brain connectivity. In addition, LIBRA has been shown to be sensitive to change in the FINGER lifestyle trial. The index has been implemented in other intervention studies as a secondary outcome, and in public health campaigns and mHealth tools to raise awareness and inform individuals about their prevention potential. Recently, the index has been updated with weights for hearing sleeping problems, sleep and social interactions and validated for dementia outcome in the English Longitudinal Study of Ageing.

**Discussion:** A worse brain-healthy lifestyle has been shown to be associated with a wide range of poor structural and functional neural markers. The LIBRA index is a useful tool for selecting participants for lifestyle-based trials, informing people about their risk profile, and can serve as a surrogate outcome in several ongoing lifestyle-based prevention initiatives.

#### **Keywords**

lifestyle, prevention, risk factors, dementia, brain, trials



### Caregiver's Voices at the CHAMP Clinic

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

5 million people are currently diagnosed with Alzheimer's Disease and this is expected to triple by 2050 (Alzheimer's Association, 2021). Behind this growing number of individuals diagnosed, is also the mounting numbers of unpaid family caregivers who care for their loved ones. Unlike a diagnosis of cancer or diabetes, dementia patients and their caregivers are not commonly provided with post diagnostic support (Kasper et al. 2015). Important research has examined the positive effects of dementia case management and how this more robust avenue of support decreases caregiver burn-out and increases quality of life for those living with dementia (Thyrian et al. 2017). However, little research has examined the application, design and delivery of this type of care and how best to support caregivers and families throughout the dementia journey. This study aims to respond to this by exploring the effects of the CHAMP (Cognitive Health and Memory Patient) model on the families enrolled based on 256 qualitative survey responses. Three main themes identified by enrolled participants, included 1. The CHAMP model itself; 2. Resources and recommendations; and 3. Being heard. Recommendations for future program design and further research are suggested with an emphasis on holistic, culturally responsive and multidisciplinary models of care for those living with dementia and their care-partners.

#### **Keywords**

Dementia, caregivers, carers, palliative care, end of life, interdisciplinary, Alzheimer's, related dementias



# The ripple effect: Outcomes of a volunteer dementia visiting program in residential aged care homes

Dr Katrina Anderson<sup>1,2</sup>, Ms Catherine Bateman<sup>1,3</sup>, **Ms Annaliese Blair**<sup>1,2</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Background:** Residential aged care facility staff are often unable to focus on meeting the person-centred emotional needs of the residents due to time and resourcing pressures. This study trialled the use of an adapted hospital Volunteer Dementia and Delirium Care Program to augment person-centred care.

**Methods:** Mixed method, non-randomised, controlled intervention study using staff, resident, and family surveys, interviews and file audits.

Two facilities recruited and trained volunteers to provide care (n=36 residents) and two control facilities continued with care as usual (n=36 residents). Comparisons were made on levels of loneliness, depression, food and fluid intake, hospital admissions, falls, physical restraint, psychotropic medication use, and quality of life (QOL).

**Results:** Outcome data on loneliness, depression, food/fluid intake, adverse incidents, medication and QOL will be presented. Most families (95%) reported that the volunteers helped a little or a lot. All volunteers agreed or strongly agreed that they were well supported and comfortable with their level of responsibility. Qualitative data indicate that families and staff believe the program provided key 1:1 person-centred interactions for residents to improve their QOL. Additionally, there was a ripple effect for staff who felt supported in their care and for families who felt reassured through the extra support provided. Key enablers where the clear structure of the program (comprehensive training, role delineation, volunteer support meetings). Challenges included ongoing volunteer recruitment, communication between families, volunteers, staff and residents, and sustainability of volunteer support and resident deterioration.

**Discussion/Conclusion:** The structured dementia volunteer program paved the way for volunteers to provide person-centred 1:1 care which enhanced quality of life for residents and had positive flow-on effects to staff and families. Online training is being developed to accelerate replication of the program.

#### **Keywords**

dementia, care, volunteers, quality of life, quality of care, person-centred care



# Music4theMind: A non-randomised feasibility trial of an individual music therapy intervention for managing the needs and symptoms of care home residents living with dementia

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Cambridge Institute for Music Therapy Research, Anglia Ruskin University, Cambridge, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Aims:** There is a growing need for developing and implementing therapeutic, psychosocial, interventions in care homes for residents living with dementia to manage the needs and symptoms of residents and enhance care quality. Using music therapy to understand and address residents' individual needs may reduce behavioural and psychological symptoms of dementia. Music4theMind aims to understand the feasibility and the clinical, organisational and cost-effectiveness of music therapy in care homes. The research also aims to enhance care quality through music therapy.

**Methods:** We have conducted a systematic review to examine how quality of care is described and measured in care home research for people living with dementia. We have also conducted semi-structured interviews with care home staff (n = 14) to understand their perspective on care quality and barriers to delivering high-quality care. To understand the feasibility and effectiveness of music therapy in care homes for people living with dementia, we have implemented a non-randomised control design in eleven care homes across England. Clinical, organisational, and economic outcome measures have been collected from all care homes pre- and post-12-week music therapy intervention and standard care groups.

**Results:** We are using mixed methods to evaluate the research. The systematic review will use a convergent design to synthesise the data. Exploratory interview data will be analysed thematically. The acceptability and practicality of music therapy will inform the feasibility of the intervention. The effectiveness of the intervention will be analysed by statistically examining within-group scores pre- and post-music therapy and between-group scores post-12-week treatment condition.

**Conclusion:** The findings will inform care organisations, policymakers, and practitioners of the potential impact of music therapy in care homes to support people living with dementia and care home staff. The research will help to shape a sustainable pathway to the delivery of music therapy in care homes.

#### **Keywords**

Dementia, Music therapy, Care Homes, Care Quality, Needs, Neuropsychiatric symptoms





# The Rise and Rise of Meeting Centres in the UK: Opportunities and Challenges for the Future

Mr Graham Galloway<sup>1</sup>, Dr Shirley Evans<sup>2</sup>, Mr Ron Coleman<sup>3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### Abstract

Dementia is an escalating global challenge, demanding innovative and sustainable psycho-social support models. The Meeting Centre model, providing community-based, person-centred support for families affected by dementia, has gained prominence in the UK. This abstract focuses on the crucial aspect of coproduction, highlighting the collaboration with individuals living with dementia that has been instrumental in reshaping the landscape of dementia care.

Introduced to the UK in 2014 through the MeetingDem project, led by Professor Rose-Marie Droes, Meeting Centres UK was subsequently established in 2018, led by the Association for Dementia Studies at the University of Worcester.

The presentation traces the historical evolution of Meeting Centres, underscoring the pivotal role played by individuals living with dementia in their development. Coproduction has transformed these centres into spaces where professional expertise intertwines with the wisdom of those directly impacted by dementia. This approach ensures that the unique needs and perspectives of individuals with dementia are central to the design and implementation of support services.

While acknowledging successes, the presentation will address challenges encountered in coproducing Meeting Centres, exploring the delicate balance required for meaningful involvement, stigma reduction, and inclusivity. Insights into collaborative strategies that have navigated these challenges successfully are shared, resulting in Meeting Centres that authentically reflect the diverse voices within the dementia community.

Looking ahead, the presentation will emphasise the continued importance of coproduction in shaping Meeting Centres. It discusses untapped potentials and emerging opportunities for further collaboration between professionals, communities, and individuals living with dementia. As the demand for dementia support grows, exploring avenues for co-designed interventions that empower and resonate with those at the heart of the experience becomes imperative. The presentation concludes with a forward-looking perspective on how Meeting Centres can evolve as true co-produced spaces, fostering a sense of ownership and empowerment among individuals living with dementia.

#### **Keywords**

Psycho-social, Meeting Centres, Dementia Friendly Communities, Coproduction, Codesign, Empowerment, Community, Person-centred.



A researcher's dilemma: How to facilitate widespread uptake of an evidence-based psychosocial intervention such as the NYU Caregiver Intervention in the face of organizational and cultural impediments, while encouraging fidelity to its essential elements

Prof Mary Sherman Mittelman, Ms Cynthia Epstein

NYU Langone Health, New York, USA

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

The goal of the NYU Caregiver Intervention (NYUCI), is to improve social support for the primary family caregiver of a person with dementia through individual and family consultation and ongoing access to support as needed. The NYUCI has a set structure, but its content can be modified to be compatible with the traditions of different cultures and the needs of each family. The original developers wrote training materials and a certification exam for potential providers, and were involved to varying degrees in the design and oversight of additional replications and translations. While, from a scientific perspective, fidelity to the original is essential, this was not always practical. The intervention has been adapted by subsequent users and modified versions have been tested and found to be effective in many sites around the world. When, in one research replication that required monitoring of a drug for people with dementia, the number of family sessions was cut from the original 4 to 3, the intervention still reduced caregiver depression, one key outcome of the original study. Another replication with adult child caregivers often didn't include other family members, but focused on family issues instead, had similar outcomes to the original, reducing caregiver depression and postponing residential care placement, although the effects were not as large. In a community translation, some participants received fewer than the original six counseling sessions due to administrative issues, the results were similar to, albeit smaller than those of the original study. In conclusion, some deviations from the original evidence-based intervention may make it less effective but more feasible and economical. Herein lies the dilemma for the researcher: insistence on total fidelity may make it less likely that the essence of the intervention will be available to many of the caregivers who otherwise might receive its benefits.

#### **Keywords**

psychosocial intervention, family caregiver, treatment fidelity



### Intergenerational Dementia Intervention - The Buddy Programme

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

In Ireland, 63% of people living with dementia (PLWD) live at home in their community. The most common social supports for this cohort include day centres, social clubs and befriending services. Engaging in meaningful activities through accessing informal and community-based supports can provide cognitive and social stimulation beneficial to PLWD, helping them to maintain their activities of daily living. However, these traditional supports often do not meet the needs of all people affected by dementia. In keeping with Kitwood's ethos of person-centred care, an increase in community-based offerings is required to provide a holistic response to the needs of PLWD.

Intergenerational interventions refer to opportunities where non-familial young people and older adults are brought together to connect through meaningful activities. The Buddy Programme is an online intergenerational psychosocial intervention where PLWD are matched with a teenaged student "buddy" for 6 weeks. Following semi-structured interviews investigating general mood levels and feelings of social connectedness, participants with dementia are matched to a student buddy based on their interests and passions. Meeting weekly online, the pairs decide on a shared activity relevant to their interests. They engage in this activity (such as watercolour painting, a knitting project or building a sporting moments playlist) whilst getting to know each other. The flexibility of this intervention also allows for freeform spontaneity during the sessions. Data was collected through semi-structured interviews and focus groups before and after the intervention. Participants also recorded brief journal-style entries after their sessions to capture their immediate feelings of the experience.

This presentation will provide an overview of the results of the thematic analysis of this work, including how intergenerational interventions help people to see beyond the dementia. Finally, highlighting the strengths, limitations and impact will offer recommendations for the development and implementation of future iterations of this kind of support.

#### **Keywords**

Psychosocial, intergenerational, community-based support,



# The NOMAD project. On the implementation and evaluation of an interprofessional model of non-pharmacological dementia care set up in North Macedonia

**Dr Milos Milutinovic**<sup>1,2</sup>, Miss Svetlana Iloski³, Dr Ljubisha Novotni¹, Dr Marija Taneska³, Dr Shpresa Hasani⁴, Dr Boban Joksimoski⁵, Dr Ivan Chorbev⁵, Miss Vildan Dogan⁶, Prof Alexander Kurz⁶, Dr Julia Fisher⁶, Prof Timo Grimmer⁶, Prof Antoni Novotni¹,², Prof Gabriela Novotni⁴,²

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Aims:** The NOMAD project implements and evaluates an innovative model of interprofessional dementia care that aims at improving the quality of life of community-dwelling persons living with dementia and their family care partner(s).

**Method:** Over the period of 9 months, three interprofessional teams of social workers and nurses – so called 'mobile memory teams' – conducted four home visits to each of 60 families living in underserved rural areas in North Macedonia. During the home visits, the teams surveyed the living situation of the families and their needs. In close cooperation with general practitioners, the memory teams developed and implemented customized packages of non-pharmacological measures equipped to improve the quality of life of both the person living with dementia and their family care partner(s). The intervention was evaluated in a cluster-randomized control study, involving in total 120 families.

**Results:** The data collection is being finished. At the time of submission, the analysis of the questionnaire data is in progress. The analysis will be completed by the end of 2023.

**Conclusion:** The results will show (1) to what extent the intervention is able to increase the quality of life of families living with dementia in rural regions and (2) whether people and their family care partner(s) benefit equally from the intervention. Next to North Macedonia, the care model introduced may also have implications for healthcare policy in other countries.

#### **Keywords**

Dementia care, non-pharmacological approach.





# Towards sustainable change: Evaluating the implementation of the Together for fun! program in community organizations

#### **Prof Sandra Harrisson**

University of Ottawa, Ottawa, Canada

#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

Together For Fun! (TFF) is a program aimed at helping people living with a neurocognitive conditions and their caregiver to rediscover pleasurable moments within their relationship. The program is offered over a 10-week period. TFF takes place in two phases: 1) leisure activities are organized for all dyads, and 2) caregivers take part in a facilitated discussion group and the person living with dementia continue the activities accompanied by a facilitator. Over the course of the meetings, caregivers are invited to reflect on opportunities to reconnect with their loved one, and to consider some of the positive aspects of the caregiver's role. The aim of this communication is to present the results of the implementation process, in order to inform program developers about the elements to consider in order to ensure the long-term implementation of an intervention in a community setting. Supported par Azjen's theory, this article analyzes the implementation process of TFF within six community organizations (2021-2022) and to highlight the influencing factors leading to change in stakeholders' behaviour. The data was collected during two focus groups held in the fall of 2022 and then analyzed using a continuous thematization (Paillé and Mucchielli, 2021). The results show that although attitudes, norms and the notion of control are favourable to intention to change the behaviour, mediating resources such as funding and mentoring by the research team are essential for lasting implementation of the program. We can confirm that the TFF program has been successfully implemented in five of the six community settings recruited. Only the resource that tested the intervention in the final months of the project is questioning its integration into its activity calendar. The participants reported that TFF makes such a difference to their daily life, reduced social isolation and contributed to maintaining people in their homes.

#### **Keywords**

neurocognitive condition; memory loss; pleasurable moment; change of practice; program implementation; leasure activities; carers; caregiver's role; organization; community; social isolation



# Artful Approach: Educating dementia carers in visual art activities to support their caregiving efforts

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<sup>1</sup>University of Michigan School of Art & Design, Ann Arbor, USA. <sup>2</sup>University of Michigan Michigan Medicine, Ann Arbor, USA

#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

Art programming for people living with dementia supports carers in their effort to provide meaningful activities that promote social interaction and personal expression. However, art programs for this community are limited in their availability and instructing visual art activities for people living with dementia requires expertise in both dementia care and art. This is often outside the scope of a carer's comfort zone despite the benefits of art training to provide carers with new methods to communicate and engage with their loved one. Recognizing the potential benefits of the arts to assist carers in their daily interactions, the presentation will discuss Artful Approach, a virtual visual art program for informal carers to learn how to facilitate art activities for persons living with dementia. Designed by an interdisciplinary team of researchers, the presentation will outline key criteria used to develop the art activities and provide an overview of the projects selected for the three-week program. The presentation will discuss the benefits of building custom art kits to promote accessibility and boost carers' confidence in leading the activity. The presentation will also discuss the program's training materials including key guidelines to aid facilitation, strategies for modifying projects and inviting participation, and suggestions to further conversation. The presentation will summarize results from a program survey to assess the structure of the program, selected activities, likelihood of future use, and identification of new skills participants gained from the program that could apply to their role as a dementia carer. Having completed the third round of programming, lessons learned from the Artful Approach research team will also be shared for replication. The presentation will highlight the need to develop virtual programs to assist carers while presenting evidence for the ways the arts enrich the quality of life for families living with dementia.

#### **Keywords**

Informal dementia carers, visual art, virtual program



# Participatory methods in designing digital health interventions for informal caregivers of people with dementia. A systematic review

**Ms Anna Messina**<sup>1</sup>, Ms Anna Maria Annoni<sup>1</sup>, Dr Rebecca Amati<sup>1</sup>, Ms Beatrice Bano<sup>1</sup>, Mr Giovanni Franscella<sup>2</sup>, Prof Emiliano Albanese<sup>1</sup>, Dr Maddalena Fiordelli<sup>1</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Aims:** The growing use of technology in healthcare has contributed to the development of digital interventions also for informal caregivers of people living with dementia. However, the marked heterogeneity of interventions poses challenges in evaluating their effectiveness. We did a review to delineate the distinctive features and development of the interventions, with focus on participatory methods.

**Methods:** We searched the following databases: Cochrane; Cinahl; Pubmed; Psychinfo: Scoups; Web of Knowledge, and IEEE, and screened and selected studies based on titles, abstracts and full texts. We used standardized procedure to abstract and synthetize relevant data of primary studies, and the Mixed Methods Appraisal Tool to assess their quality.

**Results:** Of 3136 records, 20 studies met the inclusion criteria. Most of the studies were web-based interventions, with multiple components and interactive features. The design and development of eight interventions used participatory methods with large variations in the underlying framework and application.

**Conclusions:** This review sheds light on how digital interventions for caregivers of people living with dementia are designed and developed. The limited and heterogenous use of participatory methods, and poor reporting of procedures hamper the consolidation of results and understanding of the reasons underpinning the heterogeneity in the efficacy and implementability of existing interventions. Better and formal standardizations of participatory research methods are needed to design, develop, and evaluate digital interventions for caregivers of people with dementia.

#### **Keywords**

carers, participatory research, online interventions



# The big impact of little things: the valued care strategies incorporated into the daily care of people living with dementia in care home settings under the underdeveloped dementia care services in rural areas of China

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#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

Aims As their dementia progresses, individuals can become more dependent on others and the care provided for them assumes pivotal significance for their quality of life. In China, there is an increasing demand for long-term institutional care services for people with dementia. However, the development of dementia care services within care home settings is in its infancy. Thus, we are aiming to understand the lived experience of caregivers in taking care of people with dementia and exploring the meaningful care strategies they adopt despite working in an underdeveloped and under-resourced context.

Method We are undertaking a qualitative study applying the methodology of interpretative phenomenological analysis (IPA). Twenty-three members of long-term care staff in three private care homes in rural areas of China were recruited, including care home managers (n=6), healthcare professionals (n=4), activity coordinators (n=1) and care assistants (n=12). The in-depth individual semi-structured interview was conducted as data collection. The data were analysed using interpretive phenomenological analysis.

Results We have identified the following meaningful and positive care strategies from the participants' care experience, including (1) a highlighted personalised approach as the basis of providing care, (2) the caring and attentive attitudes of caregivers affected by the social and cultural incentives and (3) building rapport and emotional bond with people with dementia.

Conclusions From the lived experience of caregivers, we acknowledged that also there were deficiencies during the deliver of care services to people with dementia, but there are still valued care strategies that are incorporated into daily care can be exhilarating.

#### **Keywords**

Dementia care, long-term care settings, qualitative study





### Using electronic healthcare record data in the evaluation of the Dementia PersonAlised Care Team (D-PACT) intervention

**Dr Stuart Spicer**<sup>1</sup>, Dr Tomasina Oh<sup>1</sup>, Dr Hannah Wheat<sup>1</sup>, Mrs Margaret Hart<sup>1</sup>, Miss Hannah Shafi<sup>2</sup>, Prof Antonieta Medina-Lara<sup>3</sup>, Dr Sonia Dalkin<sup>4</sup>, Dr Angela Bate<sup>4</sup>, Prof Richard Byng<sup>1</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

D-PACT is a primary care-based intervention for people with dementia and their carers. It provides a model of support in which dementia support workers (DSW's) link with healthcare professionals to meet the needs of people with dementia, including mental health, physical health, social goals and quality of life. Our realist longitudinal mixed-methods evaluation of D-PACT encompasses several types of data, including interviews, case studies and quantitative outcome data. A key component of this evaluation is utilising data from electronic healthcare records, alongside these other types of data, to assess the impact and effectiveness of D-PACT. This includes important actions, such as DSW's acting as a point of contact between services, communicating the needs of patients, and alerting others to a change in situation that could escalate into a crisis. It also includes resulting outcomes, such as healthcare professionals collaborating on the care of the person with dementia, or a potential crisis being avoided (i.e. "near miss" events). In addition to this, the healthcare records are being further evaluated (alongside other types of data) for a health economics analysis, with a particular focus on shifting care from hospital admissions to primary care and community settings. This presentation will provide an overview of how we extracted, managed and analysed electronic healthcare record data, how we evaluated it alongside other types of data, and what we learned from this; both in terms of D-PACT and dementia research more broadly.

#### **Keywords**

dementia, support, care, personalised, electronic healthcare records, evaluation, mental health, physical health, quality of life, wellbing, primary care.



### Living Well with Dementia: A Qualitative Study of The Lived Experiences of Persons Living with Mild Dementia in Singapore

**Miss Jasmine Gomez**<sup>1</sup>, Ms Koh Hwan Jing<sup>1</sup>, Dr Lim Sok Mui, May<sup>2</sup>, Miss Cheng Tzai Tung<sup>2</sup>, Miss Caris Ng En Qi<sup>2</sup>, Miss Tan Yun Ning Joanna<sup>2</sup>, Miss Han Jia Ern<sup>2</sup>

<sup>1</sup>Dementia Singapore, Singapore, Singapore. <sup>2</sup>Singapore Institute of Technology, Singapore, Singapore

#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

**Aims:** The increasing prevalence of dementia, coupled with Singapore's aging population, calls for an urgent need to ensure ample care and support for those living with the condition. This study aims to investigate the ways in which persons living with mild dementia adapt and adjust to the various aspects of their lives post-diagnosis, and discover effective supports and coping strategies utilised to uphold optimal levels of well-being.

**Method:** An inductive thematic analysis of semi-structured interviews with eleven persons living with mild dementia and four caregivers was carried out. The Model of Human Occupation and Adjusting-to-Change model were used to guide the development of the interview questions.

**Results:** Several extrinsic and intrinsic factors were found to have influenced (i) the participants' ability to adjust to the evolving needs brought about by their condition and the overall management of their daily activities, (ii) their ability and willingness to renegotiate their roles and (iii) their feelings of satisfaction towards their life, following their diagnosis. Primarily, this study reinforced that experiences with dementia are highly individualised, and identified familial, environmental, and personal supports to have played a significant role in enabling persons living with dementia to live as well as possible post-diagnosis.

**Conclusion(s):** Care professionals can support persons living with dementia, especially during the early stages of dementia, by identifying personal motivators, promoting positive coping mechanisms, exploring practical strategies, and involving their family members when providing post-diagnostic support services. Programmes and initiatives centred around empowerment can help promote positive volition and adaptation to the changes that arise. Efforts should also focus on enhancing environmental supports to enable persons living with dementia to be active participants and manage their life satisfactorily in their community.

#### **Keywords**

mild dementia, adjusting to change, MOHO, coping strategies, singapore





# The potential effects of a six-week training program for gait aid use in older people with dementia with unsteadiness of gait: A pilot study

**Dr Den-Ching Angel Lee**<sup>1</sup>, Dr Elissa Burton<sup>2</sup>, Dr Claudia Meyer<sup>3</sup>, Prof Terry Haines<sup>1</sup>, Dr Susan Hunter<sup>4</sup>, Prof Helen Dawes<sup>5</sup>, Dr Plaiwan Suttanon<sup>6</sup>, Ms Stephanie Fullarton<sup>2</sup>, Dr Fiona Connelly<sup>7</sup>, Prof Julie Stout<sup>1</sup>, Prof Keith Hill<sup>1</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Aims:** Gait aid use has been associated with increased fall risk in some people with dementia. This study examined the potential effects of a gait aid-training program for people with dementia on spatiotemporal gait outcomes, perception of use, and falls with gait aid use.

Methods: Community-dwelling older people with diagnosed dementia/cognitive impairment (RUDAS score≤22/30) and unsteady gait were recruited for a 6-week gait aid-training program, consisting of four physiotherapy home visits of 30 minute-training at week 1, 2, 3&6, and enhanced by carer-supervised practice. Falls and physiotherapist's evaluation of participants achieving safe gait aid use during and post-program were recorded. Perception ratings using Likert-scales at each visit, spatiotemporal outcomes using the gait aid (Time-Up-and-Go-test, 4m-walk-test, Figure-of-8-Walk-test with/without a cognitive task) at weeks 1&6, and 6&12 (6-week post-program) were examined with ordinal logistic regression.

**Results:** Twenty-four older people and their carers participated. Twenty-one (87.5%) achieved safe gait aid use at program completion. Twenty falls occurred (15 during and five post-program). Only one faller was using their gait aid when they fell. Walking speed, step length and cadence improved significantly when walking with the gait aid at week 6 compared to week 1. No significant improvements in spatiotemporal outcomes were retained at week 12. Physiotherapists were more likely to agree that gait aid use had improved walking safety among older people with dementia with subsequent training visits.

**Conclusion:** Larger studies to investigate the effectiveness of extensive gait aid training in this clinical group are needed.

#### **Keywords**

Gait aid, dementia, training, spatiotemporal, gait, falls, physiotherapist, safety



# Physical Activity Levels and their Relation to Balance Performance and Fall Risk of People with Mild Alzheimer Disease

#### Dr Beliz Belgen Kaygisiz

European University of Lefke, Lefke, Cyprus

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Aim:** To investigate self-reported physical activity (PA) levels and to analyse whether there is an association between self-reported physical activity levels and balance performance, fall risk and fear of falling of people with Alzheimer Disease(AD)

**Methods:** 46 individuals (mean age: 72,32±7,62) who was diagnosed with very early mild AD (according to MRI, clinical tests) by a neurologist was assessed in this observational cross-sectional study. After sociodemographic factors have been obtained, self-reported physical activity levels were assessed with International Physical Activity Questionnaire (IPAQ), balance performance and fall risk were assessed with Berg Balance Scale (BBS) and fear of falling was assessed Falls Efficacy Scale (FES)

**Results:** Total IPAQ score was 486.13±7,62; where 31(%67) had low level PA, 12 (%26) has moderate level PA and 3 (%7) had high level PA. Physical activity score has significant correlations with balance and fall risk (r:0.446, p: 0.05). and fear of falling (r: -0.555., p:0.00)

**Conclusions:** Physical activity levels of patients with mild AD were low and associated with low balance performance, fall risk and fear of falling at very early stage of AD. Although it is known that elderly people and also AD population have low physical activity level compared to younger population, this study reveals that some fall related factors are associated with low levels of PA. This highlights importance of increasing awareness about enabling them to adopt and maintain regular physical activity as soon as diagnosed. Preventing fall risk is inevitable as falls may have lots of physical and psychological consequences.

#### **Keywords**

Alzheimer Disease, Physical Activity, Balance, Fall





# Social Health: A Broad Concept and its Small-Scale Measurement

**Prof Karin Wolf-Ostermann**<sup>1</sup>, Mrs Janissa Altona<sup>1</sup>, Mr Henrik Wiegelmann<sup>1</sup>, Mrs Marta Lenart-Bugla<sup>2</sup>, Prof Myrra Vernooij-Dassen<sup>3</sup>, Dr Eline Verspoor<sup>3</sup>, Prof Dorota Szcześniak<sup>2</sup>, Prof Joanna Rymaszewska<sup>2</sup>, Prof Rabih Chattat<sup>4</sup>, Prof Yun-Hee Jeon Jeon<sup>5</sup>, Prof Esme Moniz-Cook<sup>6</sup>, Prof Martina Roes<sup>7</sup>, Dr Marieke Perry<sup>3</sup>

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### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

### **Abstract**

**Background:** The concept of social health is receiving increasing attention in dementia research. A new umbrella concept of social health describes associations between single markers of social health and cognitive decline and dementia. Underpinnings for this concept were derived from a synthesis of theoretical, conceptual and epidemiological work, that defined individual and social environment-level domains. However, there is neither a good overview, nor empirically based recommendations of how to measure social health.

**Aims:** Our aim is to provide a systematic overview of existing instruments that measure aspects of social health; and to begin the discussion on standardised measures.

**Methods:** Based on the concept of social health, a systematic review was conducted according to the PRISMA 2020 guidelines. The online search included the databases PubMed/MEDLINE, PsychINFO, CINAHL published in English between 1 January 2000 and 6 July 2023.

**Results:** We included more than 150 studies in the review. Most of the instruments described are self-report measures, but proxy and hybrid instruments were also found. The identified instruments are distributed in broadly equal parts at the individual level of social health, covering capacities, autonomy and social participation; and also at the social environmental level, covering structure, functions and valuation. However, they often only address single aspects of social health, with no account for multidimensionality of the concept.

**Conclusion:** Developing standardised and terminologically consistent measures of social health is a task for future research, in order to develop relevant interventions that may improve conditions for living well with dementia.

### **Keywords**

cognitive decline, dementia, instruments, social health



# Rights Made Real - Empowering those living with dementia to make rights real and applicable in everyday life

### Miss Saoirse Kelly

The Alzheimer Society of Ireland, Dublin, Ireland

### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

### **Abstract**

The Irish Dementia Working Group received funding from the Irish Human Rights and Equality Commission to create a course to empower people living with dementia to understand what their human rights are and to make those rights real and applicable in their lives. The group wanted to move human rights from something intangible that exists on paper to something that can impact the lives of people with dementia in a positive manner.

In collaboration with human rights practitioners and The Alzheimer Society of Ireland team the Irish Dementia Working Group welcomed 20 people living with dementia to a four-day course in two locations to learn more about their human rights.

Along the way the group learned about human rights, about people with dementia as unique learners with specific needs and how they can continue to empower their peers.

Over 90% of respondents felt more empowered after the course and the Irish Dementia Working Group would like to share their approach and learnings.

With thanks to project collaborators, Professor Suzanne Cahill, Dr Eleanor Edmunds Ms Clodagh Whelan, Ms Saoirse Kelly, Dr Diane Doherty.

### **Keywords**

Dementia, Human Rights



# Key considerations for professionals who communicate with the public about dementia risk and prevention: An initiative led by the Dementia Carers Campaign Network.

Dr Eithne Heffernan, Mrs Helena Quaid

Dementia Carers Campaign Network, supported by The Alzheimer Society of Ireland, National, Ireland

### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Dementia is a major public health concern. It substantially impairs the physical, mental, social, and economic wellbeing of those living with it, their families, and society as a whole. Currently, dementia has no cure, and its severity increases over time. Consequently, many members of the public are eager for information about behaviours they can adopt to prevent or delay dementia. Additionally, interest is growing amongst researchers and clinicians in potential interventions to promote brain health. Research has uncovered dementia risk factors that could be modifiable (e.g., smoking, hearing loss, obesity). Communication with the public about these factors must be accessible, transparent, and sensitive to minimise confusion, mistrust, and distress. Unfortunately, dementia risk information is difficult for professionals to convey and for the public to understand, and much remains unknown about this complex subject.

We aim to identify key considerations for professionals (e.g., researchers, clinicians, journalists, public health officials) when communicating about dementia risk to the public. We are conducting round-table workshops with various dementia stakeholders (e.g., people with lived experience, clinicians, researchers, policy-makers). We are leading this initiative as experts by experience from the Dementia Carers Campaign Network: an advocacy group comprising people with experience of caring for a loved one with dementia, supported by The Alzheimer Society of Ireland. Previous initiatives in this area were typically led by professionals, despite the unique and valuable insights of experts by experience.

Preliminary findings indicate that professionals should consider co-producing messages in multiple formats with representatives of their target audience, developing an understanding of how different cultures/communities conceptualise dementia, and generating brain health guidance for carers/relatives of people living with dementia that acknowledges their limited resources and capacity. Our findings have important implications for a wide array of professionals who are tasked with dementia risk communication and brain health promotion.

### **Keywords**

Considerations



# The co-design of an Indonesian Dementia Awareness Game

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### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Background:** It is possible to live well with dementia and many people with dementia are living active lives with the support of families, friends and communities worldwide. However, in Low-Middle Income Countries (LMIC) where the largest rise of people living with dementia is being seen, there remain limited services and support. Further complicated by a lack of knowledge about dementia alongside culturally-based beliefs that may stigmatise the person living with dementia. The team have codesigned an innovative UK dementia awareness game, www.dementiagame.com, with people living with dementia and nursing students. In that study, over 1000 people played the game over a 4-week period. A prepost evaluation was completed with 500 people using the Approaches to Dementia Questionnaire. After playing the game there was a statistically significant improvement (p< 0.001) across all domains of the questionnaire, demonstrating a more positive attitude towards people with dementia.

**Aim:** To co-design an innovate serious game to enhance understanding and reduce stigma associated with dementia in Indonesia

**Methods:** Using participatory methods (drawing and storytelling), an Indonesia Dementia Awareness Game was co-designed with older people with experience of dementia in Indonesia.

**Preliminary Results:** Initial evaluation findings suggest that the game may improve the public perception of dementia in a LMIC.

**Conclusion:** This research demonstrates how co-design with people with experience of dementia can lead to promising impacts on cultural perceptions of dementia. This research makes a novel contribution to the field as, to our knowledge, it is the first Dementia Awareness game developed in a LMIC.

### **Keywords**

co-design, dementia, LMIC, awareness game





# 'Not the End of the World' – A Story of Two Actors Helping to Reduce Stigma in Ireland

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The Alzheimer Society of Ireland, Dublin, Ireland

### **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

Dementia as a disease doesn't discriminate; it reaches across generations and genders and affects people of all backgrounds. The prevalence is increasing globally, with more than 500,000 families impacted in Ireland alone. The Alzheimer Society of Ireland's vision is an Ireland where every person on the journey of dementia is valued and supported.

Whether famous or unknown, dementia can affect anyone. And when a public figure shares their own dementia journey, this can have a significant impact on increasing awareness, which has shown to reduce stigma. We can see this in a world stage context when it was announced the actor Bruce Willis has Frontotemporal dementia. And, in Ireland in 2022, the power of personal stories from those in the public eye was again to the fore when Irish actors and couple Bryan Murray and Una Crawford O'Brien shared Bryan's Alzheimer's diagnosis in an exclusive interview with a national publication. The ASI worked closely with the couple and the media outlet in the months leading up to the reveal. Bryan and Una's story – their determination to live well – put a fresh spotlight on dementia, garnering significant media interest and raising awareness and The ASI's work.

In 2023, Bryan and Una joined The ASI's National Tea Day Campaign as ambassadors to help raise vital funds and awareness for people with dementia. Their story reinforces the message: With the right support, it is possible to live well with dementia. The ASI believes that misrepresentations, particularly in media, can increase the fear surrounding the condition. While breaking down stigma and challenging misconceptions is no easy feat, we will present how a public story, about a high-profile figure living well with dementia, can tackle this and strive to have a positive impact on perceptions surrounding dementia.

### **Keywords**

Dementia awareness



# Let's Reimagine: Using Collaborative Music-Making to Challenge Stigma Associated with Dementia

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### **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

Stigmatizing tragedy discourses of dementia are pervasive. They shape attitudes, interpersonal relationships, and structures and experiences of care, and lead to fear, isolation, abuse, neglect, and suicide. Eliminating stigma is an urgent priority across the Globe. We brought together an international group of persons living with dementia (PLwD), family members, professionals, artists, researchers, and others to form Reimagining Dementia: A Creative Coalition for Justice to collaboratively work to transform the discourses, conditions, and practices that oppress and discriminate all affected by dementia. With a commitment to the power of play, imagination, and creativity in addressing social injustices, we drew on critical arts-based inquiry and liberation arts. These methodologies are effective for addressing stigma and promoting personal and social change because they are participatory and inclusive, create aesthetic and emotional encounters that challenge dominant discourses, and provide novel opportunities to interrogate, critically reflect, and foster change. The purpose of this presentation is to describe our co-created music-making project – Let's Reimagine – that aims to challenge stigma and show how PLwD can engage, connect, and live a vibrant life in community with others.

Our collaborative process involved: engaging in arts-based activities to explore what re-imagining dementia meant to Coalition members; recording interviews with PLwD and family members to explore experiences of stigma; using an adapted critical creative hermeneutic analysis process to analyse the outputs from activities and interviews and identify key messages for the song; co-creating musical riffs and lyrics for the song; working with soloists with dementia and other coalition members to audio-record different parts of the song; and creating the song-video, which involved collecting and curating photos, video clips, and art that support the song's messages.

We share our process to inspire and inform other collaborative, arts-based initiatives that aim to achieve a more just, caring, and inclusive society.

### **Keywords**

stigma, dementia, critical arts-based inquiry, liberation arts, collaborative music-making, song video



# **Dementia awareness: The Maldives Story**

### Ms Mariyam Fiyaza

Alzheimer's Society of Maldives, Male', Maldives

### **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

Alzheimer's Society of Maldives (ASM) registered in September 2019 began its activities in September 2021. ASM's aim is to improve the quality of life for persons with dementia and their Carers.

Maldives will become an ageing society in 2054 and has an over 65 years resident population of 20,850. Assandha data from 2017 to 2021 indicate approximately 1,400 persons with dementia. However, this figure does not account for persons who travel abroad independently for medical purposes and undiagnosed cases.

Lack of awareness and the misconception that dementia is a normal part of aging, locally referred to as "muskulhi bali," are prevalent issues in the Maldives. Consequently, raising awareness was the top priority for 2021 and 2022. This initiative aimed to facilitate early diagnosis and was executed through an Awareness Campaign that ran from July to November 2022.

Given the geographical and lack of data obstacles, constraints of limited manpower and funding, ASM wisely adopted the strategy that entailed leveraging online platforms, collaborating with healthcare professionals for awareness sessions, building relationships with policymakers and actively engaging with other stakeholders to foster collaboration.

The Awareness Campaign was a comprehensive effort that targeted various segments of the population through range of platforms, with significant emphasis on social media platforms. The campaign encompassed several key activities: 1) Launching Dementia Flyer and 10 warning signs of Dementia 2) Launching Dementia Song 3) Meetings and interviews 4) Publishing educational videos 5) Active participation in stakeholders' events 6) Hosting awareness sessions in Cities 7) Organizing an art competition with Dementia as the central theme. These diverse activities engaged different segments of the population and effectively raise awareness.

ADI and its leadership has been crucial in ASM's journey. During November 2022 visit to Maldives, the Ministry of Health committed to develop a National Dementia Plan.

### **Keywords**

Dementia, dementia awareness, awareness using social media



# Richness of emotion in people with dementia

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### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

It is important to explore not only what is lost with the progression of dementia, but also what is left and what can be developed. Some studies suggest that as dementia progresses, people become less expressive of emotion, and at the same time it becomes more difficult for them to distinguish between people's facial expressions. On the other hand, there are reports that even when people are not able to communicate well verbally, music therapy can help them to express rich emotions in reaction to music. How rich in emotions do people with dementia actually feel?

Designing for Dementia Hub in Japan has interviewed over 100 people with dementia since 2018. The interviews lasted 60-90 minutes per person and included both negative and positive topics, ranging from the difficulties they have to the innovations they make in their daily lives, to what makes life worth living. In the current study, the transcripts of 88 interviews conducted between 2019 and 2020 were read by the subjects (N=13), and using Paul Ekman's six basic emotions (anger, disgust, fear, happiness, sadness and surprise), they rated how strongly each person expressed these emotions in each interview on a five-point scale. The results showed that people with dementia feel a range of emotions in the interview, with happy emotions being the strongest. We also surveyed the general public to find out how rich in emotions they think people with dementia are. Comparing the image within the general public and reality, we will discuss how people with dementia have a richer inner life.

### **Keywords**

emotion, feeling, richness



# Association Between Family Caregiver Burden and Affiliate Stigma in the Families of People with Dementia

Dr Jian-An Su

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### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

Family caregivers of individuals with dementia bear a significant caregiving burden. Affiliate stigma refers to the internalized stigma experienced by individuals connected to those with dementia. However, research on affiliate stigma among caregivers of individuals with dementia and its impact on caregiver burden has been limited. Hence, our study aimed to explore the burden faced by caregivers of individuals with dementia and its association with affiliate stigma. Additionally, we investigated the factors contributing to affiliate stigma. This cross-sectional study was conducted at a general hospital in Taiwan, where we enrolled 270 individuals with dementia and their family caregivers from the outpatient department. We assessed relevant demographic and clinical data of both patients and caregivers. Regression analysis was employed to identify factors linked to affiliate stigma. Our findings revealed that 23.7% of family caregivers experienced depression, while 37.4% reported anxiety. Male caregivers exhibited higher levels of anxiety and a heavier caregiving burden associated with affiliate stigma compared to their female counterparts. Furthermore, characteristics such as younger age and lower levels of dependence in daily activities among individuals with dementia were associated with increased affiliate stigma. Notably, a greater burden on family caregivers was linked to more pronounced affiliate stigma. Implementing interventions to alleviate the burden on family caregivers may help mitigate the impact of affiliate stigma.

### **Keywords**

dementia, caregiver, caregiver burden, affiliate stigma



# Providing support for dementia carers through the co-design of education and training courses: A 3-years research project

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### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

**Background:** Dementia represents a public health priority. Worldwide, more than 55 million people have dementia, and this number is expected to dramatically increase over the next few years. In a similar scenario, the number of dementia carers will grow. As shown by prior research, caring for someone living with dementia can be challenging and stressful and, therefore, providing the right support is necessary. This should occur by offering systematized and high-quality education and training courses to dementia carers who often lack knowledge and skills to provide optimal care.

**Aims:** Within the project AGE-IT (PNRR PE8 "Age-It"), our research group aims to design, implement and evaluate an e-learning platform to be used by formal and informal caregivers, as well as by migrant care workers.

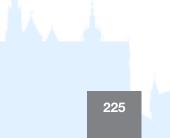
**Method:** A literature review on the topic of educational and training courses for different types of dementia carers will be carried out along with a selection and analysis of elderly care training initiatives available in Italy. Six focus groups with formal and informal caregivers will be conducted in three Italian regions as to address territorial issues due to the regional administration of the Italian healthcare system. Furthermore, 10 semi-structured interviews will be conducted with migrant care workers in the same regions. Qualitative data will be analyzed using NVivo.

**Results:** Results from our literature review along with qualitative data from focus groups and interviews will be grouped under specific themes and thoroughly described.

**Conclusions:** It is essential to develop sustainable, accessible, evidence-based training courses, by following the principles of community care, person-centred care and co-design.

### **Keywords**

Caregivers, Dementia, Psychoeducation, Training





# Building literacy, reducing stress, and changing attitudes through online dementia education.

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University of Tasmania, Hobart, Australia

### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

**Aims:** The Understanding Dementia MOOC (UDMOOC) has been providing free accessible education globally for the past ten years. More than 390,000 people have enrolled in the UDMOOC of which 45% identify as informal carers. Given its high level of sustained uptake we wished to determine the impact of the UDMOOC on informal carers.

**Method:** Using a mixed methods approach we explored dementia literacy, self-reported stress, attitudes, and behaviours associated with providing care for people living with dementia. The Consumer Access, Appraisal and Application of Services and Information for Dementia, the Dementia Knowledge Assessment Scale, the NPI-Q, and questions adapted from a model of research utilisation comprising instrumental, persuasive and conceptual domains of knowledge translation were used in an online survey to examine domains of dementia literacy and stressors associated with providing care, both before and after completing the UDMOOC. Participants were also asked open-ended questions about the impact of the UDMOOC.

**Results:** After completing the UDMOOC, dementia literacy improved significantly across all domains: knowledge, evaluation and engagement, readiness, social supports, specific dementia services and practical aspects of care. Over 70% of those experiencing stress reported that their stress level was reduced as a consequence of completing the UDMOOC. 50.9% of informal carers reported that they have used the knowledge gained from the UDMOOC when caring for someone with dementia "nearly all the time". 85% felt more prepared, 84% felt more confident as a carer and 85% felt more understanding. Thematic analysis revealed improved knowledge of dementia progression led to a change in understanding of the behaviours associated with dementia, and improved understanding of the person living with dementia led to changes in approaches to the care interaction.

**Conclusion:** The UDMOOC continues to deliver contemporary, relevant education on dementia which improves dementia literacy, attitudes and stress responses of informal carers.

### **Keywords**

dementia literacy, stressors, education, carers



# Digital health solutions in dementia care: how to discover the best products for your need

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Fundacion de Neurociencias, Oviedo, Spain

### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

The number of digital health products in the market is increasing every day. There are many digital tools that can be helpful in the care of people with dementia for a wide range of uses, such as cognitive rehabilitation, geolocalization, caregiver support, and management of behavioral disturbances. However, choosing the best digital product to cover a given specific need can be challenging.

Vadimecum.com is a free search engine with enhanced accessibility designed to help caregivers discover and select digital health solutions that match their specific requirements. Structured and complete information on each solution will help caregivers gain a comprehensive insight into any digital product, thus easing the process of discovering and comparing, so caregivers can pick the best option for their needs.

In conclusion, digital health has great potential in the management of people with dementia and support for carers. However, the huge number of digital health products existing today and the lack of truthful sources integrating them all hampers their use. Vadimecum.com is a search engine specifically developed to ease the discovery of digital health solutions with structured information on all listed products. Vadimecum can help caregivers of patients with dementia in searching and selecting the best products for their specific needs.

### **Keywords**

digital health, vadimecum, App, neurotechnology



# The Spirited Project: equipping families and friends to offer spiritual care to people living with dementia.

**Dr Eleanor Flynn**, Prof Darrell Jackson, Prof René Erwich, Dr Cathie Lambert, Dr Titus Oloruuisola University of Divinity, Melbourne, Australia

### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

**Aims:** The Spirited Project is an action research project designed to support care partners offering spiritual care to people living with dementia. Spiritual care, the provision of specific interventions or therapies to support another person's spirituality, may include aspects of religious practice or ritual but does not assume religious belief.

**Methods:** The project includes a literature review, a Delphi study, focus groups, and the development or modification of training programs to assist care partners to provide spiritual care to people living with dementia. It is being carried out in Australia and the UK.

**Results:** Our meta-synthesis (Jackson, 2022) of 244 peer-reviewed articles yielded 76 relevant English articles of qualitative research published between 2000 and 2020 on spiritual or religious care for people with dementia. Spiritual care was predominantly seen as part of holistic care. There were few systematic studies of the resources mentioned. Training packages were predominantly designed for professional carers. One study was co-designed with people living with dementia for care partners. The Delphi study comprised spiritual care professionals, aged care workers, geriatricians, old age psychiatrists, religious chaplains, and theologians. Their responses included: the challenges of caring for people with dementia, benefits of resources directed towards the promotion of meaning, benefits of reminisce therapy especially combined with sensory activities, and congruence of spiritual care values between carer and person with dementia. As training for care partners in aspects of dementia increases their caring abilities the addition of spiritual care education is appropriate. Focus groups of community carers providing spiritual care for people living with dementia will be conducted in October 2023. The findings from these groups will be collated with those of the expert Delphi group and the results used to develop or modify resources supporting the provision of spiritual care to people with dementia by care partners.

### **Keywords**

Community carers, spirituality, education, support



# Identification and Analysis of support of dementia carers in Botswana

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<sup>1</sup>Maikutlo Mabille Alzheimer's Foundation, Gaborone, Botswana. <sup>2</sup>Association of Dementia and Alzheimer's Kenya, Nairobi, Kenya

### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

Objectives: Identify and Analyse support for dementia carers in Botswana

**Background:** Informal care giving is a norm in a Setswana traditional society. Although family dynamics have been changing with time, some principles are not observed as our way of life has since become modernized. Regardless of the aforementioned, there isn't any type of system in place to support care givers, be it in form of education, counseling or welfare. Most people do not make a choice to be caregivers; it is a situation they find themselves in, which is usually dictated by unfavorable socioeconomic circumstances. Due to this fact, care given to people living with dementia is usually sub-par. Educating and training care givers could be instrumental in curbing the shame and stigma associated with Alzheimer's disease or dementia, in a society which views and associates the disease with witchcraft and insanity.

Of late, the role of care giving in our society has been susceptible to the young. They have to halt their lives to give care to their parents or the elderly in their families. This sacrifice comes with them giving up on their ambitions and dreams. At the end of the care giving journey, there is no support offered to them to integrate back in to society.

Methods: Experience and Observation

**Results:** Lack of education and training on Dementia is a major influence of stigma, taboo and abuse of people living with Dementia Botswana.

**Conclusions:** It is time for the Botswana Government to invest in world class dementia care and develops a Dementia Policy. It is necessary to the alleviation of the painful plight of those living with Dementia and their caregivers.

### **Keywords**

Education, Training





# The Effects of Mindfulness-Based Intervention for Caregivers for People with Dementia on Physical and Mental Health Wellbeing

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Taipei Medical University, Taipei, Taiwan

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

### **Abstract**

With the increasing trend of aging and declining birth rate, the population suffering from dementia is also increasing year by year all over the world, so the demand for dementia caregivers is also increasing. Dementia is a progressive and incurable disease. Caregivers cannot stop facing these pressures and burdens. They have to sacrifice their working time to take care of these patients. It shows that the problem of dementia caregivers is no longer a personal matter, but will affect the country's economy and become a social problem. The research literature has seen a surge in research on mindfulness-based stress reduction both as a form of psychotherapy and as a form of clinical intervention. Mindfulness-based stress reduction (MBSR) group training programs have been introduced in the medical, academic and educational circles (Germer, Siegel & Fulton, 2005). Most mindfulness-based stress reduction exercises lasted about an hour once a week for eight weeks, and require a lot of time commuting, so caregivers may not participate continuously due to lack of time. Therefore, the difference try to invite the dementia caregivers to conduct short-term intensive mindfulness-based stress reduction exercises at home for 10 minutes a day for four weeks, combined with the currently commonly used mobile phone software to help the caregivers reduce stress and to improve their physical and mental health.

### **Keywords**

mindful stress reduction, dementia caregivers, quality of life, heart rate variability



# Carers - the untapped resource of specialist knowledge.

### Ms Mary Clare Whitaker

Individual, UK, United Kingdom

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

### **Abstract**

After Caring for my husband with Young Onset Alzheimers Disease for 8 years now, I realise that I am a font of specialist knowledge and so are those other Carers I have met along the way. Yet as governments and organisations struggle to supplying consistent and relevant information for this cohort - they constantly overlook the value of peer support.

It is widely known that the most common emotions felt when one receives the diagnosis of dementia, is isolation and bewilderment. It is also commonly known that most carers are exhausted. Exhaustion is not conducive to creating practical and innovative self help schemes - and yet if we could just have a blue print with a simple structure for this, we could turn so much frustration and darkness into a place of knowledge and enlightenment.

When you receive a diagnosis of Alzheimer's, wherever you are in the world, you should be able to 'opt in' to a Connecting Service from your Health Care Provider - to enable you to link up with other families in similar situations. Preferably on a local face to face level.

We need to change the aftermath of diagnosis. Let us get together in groups and help one another with our joint knowledge in a positive way. Let us do it for ourselves at a place and time of our choosing.

What communities need is a more holistic and ordered facility to draw together people living with Alzheimer's - a blue print which can be rolled out to already functioning gathering spots - libraries, village halls etc. A readymade action plan enabling people to engage regularly - to share expert Caring knowledge, to create peer led, mini pockets of excellence in Dementia care knowledge and understanding.

### **Keywords**

peer support, self help, Carers knowledge, untapped source, centres of excellence, blueprint for change,



# Share the Care: Proven Strategies to Support Dementia Care Partners

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<sup>1</sup>Share The Care, Orlando, USA. <sup>2</sup>CareVirtue, San Diego, USA

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

### **Abstract**

Share the Care is a not-for-profit organization providing services, education, training, and support to dementia care partners, enabling them to support the person living with dementia at home, delaying or eliminating the need for institutional care.

Share the Care's integrated approach to support dementia carers includes utilizing CareVirtue, an evidence-informed technology platform, to improve carer outcomes with an innovative model:

**Case Management:** a professional case manager meets with the primary care partner to assess needs and discuss options for support and services, i.e., the type, frequency and the ability of the person living with dementia to participate in care choices. Our case managers develop a comprehensive plan and works with the care partner to put it into action.

Share the Care operates four licensed **Adult Day Care Centers**. The centers provide a wide range of specialized and cognitively enriched program activities for people living with dementia. All programs are client-centered, promoting client potential and dignity. Clients are provided with outlets for self-expression, creativity, socialization, and opportunities to develop friendships, utilize skills, life experiences, and to feel productive, loved and valued.

Carer Behavioral Health Services: Share the Care offers a team of qualified and compassionate therapists to support dementia care partners. We offer one-hour virtual individual counseling sessions on a weekly basis. Counseling is tailored to specific caregiving needs and may address caregiver fatigue, grief and loss, stress management, depression, anxiety, adapting to change, trauma, transitions and more.

### **Learning Objectives:**

- Demonstrate strategies to amplify best practices and programs for organizations using technology to improve services and reduce burden for dementia care partners.
- Understand how carer support agencies using technology can improve an organization's communications strategy, social impact and reach.

### **Keywords**

dementia carer services, dementia carer, dementia care partner



"I have accepted my father's death; I was not sad but relieved." Adaptive grief responses for bereaved dementia care partners: A scoping review.

Ms Gemma ODonnell, Dr Zachary G. Baker

Arizona State University, Phoenix, USA

### **Topic**

Support for dementia carers: Informal carers support - pre, during and post

#### **Abstract**

**Background:** Bereaved dementia care partners are particularly susceptible to prolonged grief disorder post-death due to the protracted caregiving demands and progressive course of dementia. Limited research focuses on the bereaved dementia care partner and the methods they use to grieve adaptively.

**Aims:** This scoping review explores findings from the psychological and medical literature on the adaptive grieving experiences of bereaved dementia care partners and integrates what healthcare professionals can do to support bereaved dementia care partners transition into a post-death role.

**Methods:** A systematic search of databases PubMed, PsycINFO, CINAHL, and Scopus was conducted. Studies published between 2013 and 2023, written in English, and focusing on adaptive grief responses for bereaved family care partners of persons with dementia met the inclusion criteria.

**Results:** Of the 10 included studies, three overarching adaptive grieving themes emerged: 1) social health, 2) emotional fitness, and 3) reclaiming activities. Bereaved dementia care partners frequently reported finding significance in their caring experience, practicing self-care, redefining self-identity, seeking social support, and participating in bereavement support groups. Many bereaved dementia care partners experienced a complicated mix of emotions, combining loss with personal growth and a better understanding of dementia.

**Conclusion:** Future study should look at the factors that influence adaptive grief responses, as well as their long-term impact on the mental health and quality of life of grieving dementia care partners. Understanding these patterns can help healthcare professionals facilitate appropriate care and support for this vulnerable population.

### **Keywords**

Complicated grief, Alzheimer's disease, mourning, death, informal carer, neurodegenerative disorders



# **I10-005**

# Exploring the experience of social and professional support on grief and the impact of caring in family carers of people living with dementia

Mrs Sophie Crawley<sup>1</sup>, Dr Nuriye Kupeli<sup>1</sup>, Dr Victoria Vickerstaff<sup>2</sup>, Dr Kirsten Moore<sup>3,4,5</sup>

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### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

### **Abstract**

**Introduction:** Caring for somebody with dementia can have a profound impact on carer wellbeing. To address the existing gap in knowledge, we aimed to understand how different types of social and professional support relate to grief and the impact of caring.

**Method:** Mixed methods cohort study. The Caregiver Grief Scale, Zarit Burden Interview and validated measures of social and professional support were completed; satisfaction with support, received support, negative interactions, social network, social support for health, feeling understood by professionals, coordination between care teams and satisfaction with care at the end-of-life in dementia (n=51). Univariate regressions explored the influence of support on grief and burden. Eight participants additionally completed a qualitative interview. Transcripts were thematically analysed.

**Results:** Most carers were female (66.7%) caring for a parent (72.5%) with moderate to severe dementia (84%). A larger social network (coefficient 0.946, 95% CI (.003, -1.888), p=0.049) was associated with higher grief. Fewer negative interactions (coefficient 1.434, 95% CI (.591, -2.277); p=0.001) and greater social support for health (coefficient -6.081, 95% CI (-11.247, -0.926); p=0.022) were associated with lower burden. Less coordination between care teams was associated with higher grief (coefficient -.379, 95% CI (-.726, -.032), p=.033) and burden (coefficient -.601, 95% CI (-.938, -.264), p=.001). Qualitative analysis identified the importance of support understanding, "getting it", with trust in support enabling meaningful support utilisation.

**Conclusion:** Trust as a crucial mechanism needed for support to be beneficial provides insight into the unexpected association between a larger social network and higher grief. Facilitating carers to understand, identify and access meaningful support may positively impact grief and burden. The impact of professional support being less coordinated emphasises the need for improved service integration, whilst qualitative findings indicate carers would feel more supported if they felt health care professionals really understood their experiences.

### **Keywords**

Family carers, grief, support



# Once a man, twice a child: A phenomenological study of women of Jamaican heritage caring for a relative living with dementia.

### **Dr Janet Bailey**

Black Country NHS Foundation Trust, Dudley, United Kingdom. University of Wolverhampton, Wolverhampton, United Kingdom

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

This study offers a unique and original contribution to our knowledge base as currently there is no qualitative study that focuses on dementia caregiving in Jamaican families. Socio-cultural traditions in Jamaican families assign nurturing and caring roles to women so that when a family member develops dementia it is females who take up the role.

Using a phenomenological methodology, data were collected in England and Jamaica over a period of twelve months with ten women of Jamaican heritage caring for a family member living with dementia. Participants were interviewed in Birmingham, England and Kingston, Jamaica. The caregiving experience of the ten participants spanned across the health and social care systems of the Jamaican Diaspora in England, Canada, and the US. These in-depth, face-to-face interviews with caregivers provided rich data. Findings revealed six themes relating to how women of Jamaican heritage experience and understand dementia caregiving. (1) strength and resilience; (2) a labour of love; (3) picking sense out of nonsense; (4) I'm not a carer - I'm family; (5) the role of the Church and (6) Jamaicans don't do that. The insight gained from these findings provided rich information about the participants' experiences of caregiving.

This study revealed that cultural values and upbringing within Jamaican families are important factors that support caregivers in dealing positively with the demands of caregiving. The main implications for practice from this study suggests is that the willingness and commitment of women of Jamaican heritage to provide long-term care within family units to maintain the dignity of their elders, as opposed to admitting them to care facilities, needs affirming and supporting. Also, there is a need for commissioners of services and support in England and Jamaica to recognise the importance of voluntary community groups and Black majority churches, when collating and disseminating information.

### **Keywords**

dementia caregivers, Jamaican



# THE MEMORIES THAT REMAIN: MEMORIES OF DAD, ME AND ALZHEIMER'S DISEASE

#### Mr Guillermo Ferro

Asociación Lucha contra el Mal de Alzheimer y Alteraciones semejantes de la República Argentina (A.L.M.A.), Buenos Aires, Argentina

## **Topic**

Support for dementia carers: Informal carers support – pre, during and post

### **Abstract**

This non-fiction novel is a first-person account of Alzheimer's Disease seen as a family experience. It is presented from the point of view of a son who cares and supports his father. Through the book, the son not only feels for his father, but also talks about the pain caused by his mother's grief as the main caregiver.

The book portrays a life story, a love story, a story about the last years of the father's life and the experience shared after the diagnosis. The author describes the progression of the disease through stories and anecdotes that happened during the last years.

This book is somehow the author's need to express himself through writing his own sensations, fears and grief. It is also tribute to his father, a way to immortalize him, to make his story transcend. Furthermore, the book is intended as a tool to help others. Not all experiences are the same, but each one contributes and teaches us new things that can be useful to others. This book seeks to make one's own experience and the stories of this history useful for others, to accompany, to think, to reflect.

About the author: Guillermo Ferro was born in Córdoba in 1979. He has a degree in Social Communication and is a volunteer of the Asociación Lucha contra el Mal de Alzheimer y Alteraciones semejantes de la República Argentina (ALMA), where he produces and hosts a weekly radio program called LA VOZ DE ALMA.

The book was edited and designed by Lago Editora (Córdoba), and published in November 2021. In May 2022 it was chosen by the Program of Stimulus to the Cordobesas Literary Editions of the Legislature of Córdoba.

### **Keywords**

Libro, Alzheimer, demencia, cuidadores



# Time for Dementia: Innovation in healthcare student dementia education

**Dr Stephanie Daley**<sup>1</sup>, Dr Molly Hebditch<sup>1</sup>, Mrs Yvonne Feeney<sup>1</sup>, Mr Thabrez Khan<sup>2</sup>, Prof Sube Banerjee<sup>3</sup>
<sup>1</sup>Brighton and Sussex Medical School, Brighton, United Kingdom. <sup>2</sup>Alzheimers Society, London, United Kingdom. <sup>3</sup>University of Nottingham, Nottingham, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Aims:** The future healthcare workforce requires the skills, attitudes, and empathy to better meet the needs of those with dementia. Time for Dementia is an educational programme in which healthcare students from a range of professional groups visit a person with dementia and their family carer over a two-year period. The aim of this study was to evaluate the impact of Time for Dementia on student attitudes, knowledge and empathy towards dementia.

**Methods:** A mixed methods longitudinal cohort study was conducted between 2014- 2021. Qualitative interviews and focus groups were undertaken with 93 healthcare students. Measures of dementia knowledge, attitudes and empathy were administered to students at five universities in the south of England before and after they completed the Time for Dementia programme. Data were also collected at equivalent time points for a control group of students who had not taken part in the programme. Outcomes were modelled using multilevel linear regression models.

**Results:** 2,700 intervention group students and 562 control group students consented to participate in the research. Students undertaking the Time for Dementia programme had higher levels of knowledge and positive attitudes at follow-up compared to equivalent students who did not undertake the programme. Key themes identified from the qualitative analysis highlighted relational learning, insight and understanding, challenge (of) attitude and stigma and enhanced dementia practice.

**Conclusions:** The results suggest the Time for Dementia programme is effective in improving the knowledge and attitudes of healthcare students across different professional groups and universities.

### **Keywords**

Dementia, Healthcare Education, Students, Lived Experience





# Dementia awareness for sports clubs and venues: an innovative, person-centred training course for frontline staff in collaboration with people with dementia

### Mr Matthew Hughes-Short

Alzheimer's Society, London, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

Evidence suggests spectating live sport can have positive social and psychological outcomes. However, many people with dementia feel they cannot continue attending live sport post-diagnosis. Insight shows that negative experiences with frontline sports staff can exacerbate barriers for people with dementia. Frontline staff are often the only point of contact for people with dementia on matchday. Negative experiences therefore carry reputational and customer retention risks for sports venues.

As part of Alzheimer's Society's Sport United Against Dementia campaign, the charity collaborated with people with dementia to create new training for frontline staff.

#### This aimed to:

- raise awareness of the challenges people with dementia face attending sport
- change behaviour of staff by improving self-efficacy and personal role effectiveness
- support senior staff members to cascade learning across their organisation

Content was developed utilising co-production with people with dementia. An interactive, train-the-trainer delivery model was developed, emphasising a person-centred approach and skills-based learning. Case studies and scenarios were used to demonstrate the challenges people with dementia experience. Sessions were delivered by a learning specialist, alongside people with dementia, and Dementia Advisors to encourage local service collaboration. Pilot sessions were delivered at four professional sports venues hosting elite sport.

Outcome evaluation showed universal improvement in dementia knowledge, confidence when supporting people with dementia, and ability to advise colleagues on good practice. Process evaluation highlighted co-delivery by a person with dementia as emotive and impactful. There were additional high ratings for the format and post-course digital support provided.

This work highlights the importance of industry-specific staff education and co-production with people with dementia. Pilot success has led to further live training being delivered with all 20 Premier League clubs. Development of a Community of Practice has begun to foster the sharing of good practice, alongside using virtual reality to further enhance delivery.

### **Keywords**

Sport and Dementia, Dementia Friendly Stadia, Co-Production, Person-Centred Support, Train-the-trainer



# Engaging families affected by dementia in undergraduate education: experiences of being 'experts by experience' in Time for Dementia.

Dr Molly Hebditch<sup>1</sup>, Dr Stephanie Daley<sup>1</sup>, Ms Yvonne Feeney<sup>1</sup>, Prof Sube Banerjee<sup>2</sup>

<sup>1</sup>Brighton and Sussex Medical School, Sussex, United Kingdom. <sup>2</sup>University of Plymouth, Plymouth, United Kingdom

### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

### **Abstract**

**Aims:** to evaluate the satisfaction and views of families (people with dementia and their family carers) who volunteered in Time for Dementia (TFD).

TFD is an educational programme in which healthcare students visit a person with dementia and their family carer over two years. People with dementia and their carers are our 'experts' and teach students about life with dementia, healthcare experiences, and what helps them to live well with dementia. Since 2014, 2,100 families have volunteered in the programme in the UK.

**Method:** A mixed-method evaluation of family satisfaction in the programme was conducted between 2014-2021. Families hosted students from five universities in Southern England, in medical, nursing, and allied health professions. 442 families completed a satisfaction survey. Multiple linear regression models for factors associated with total satisfaction scores were produced, and qualitative data were analysed using thematic framework analysis.

**Results:** Overall satisfaction for taking part in TFD was high, and higher satisfaction was significantly associated with a higher number of student visits. Families indicated they felt able to contribute to student learning and identified benefits for themselves in taking part including valuing the social interaction. Suggested improvements include increased visit structure and organisation.

**Conclusion:** This study contributes to the broader understanding of what 'Experts by Experience' value when taking part in educational interventions. Volunteering to contribute to undergraduate education can be satisfying for people with dementia and carers and can lead to reciprocal benefits between students and families. TFD is one successful model for this.

### **Keywords**

Healthcare Education, Experts by Experience, Patient Educators





**The UK Social Care Workforce:** Turning policy into practise through influencing rooted in evidenced-based policy recommendations, to tackle decades of underfunding and neglect.

### Mr George Parish-Wallace, Mrs Ashton Fitzell

Alzheimer's Society, London, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

Although one in three people in the UK born today will go on to develop dementia in their lifetime, the current social care system is not fit for purpose. An over-stretched, under-supported workforce must focus on essential tasks, which are necessary to stay safe and healthy on a day-to-day basis but will not necessarily provide a good quality of life. It doesn't reflect the personalised care that supports people to live well, with choice and control, and maintain their relationships.

There are record staff shortages, high staff turnover rates, low pay, and staff face limited advancement opportunities. Alarmingly, many lack the knowledge and training to effectively support people with dementia.

In this presentation, we dissect the need to implement rigorous evidence-based training, including mandatory level of dementia training for all care staff to tier 2 of the Dementia Training Standards Framework. We cover our calls for a 10-year social care People Plan in England, with more investment in training and development to attract and retain staff, reiterated by the All-Party Parliamentary Group on Dementia in its Workforce Matters report.

Additionally, we examine Alzheimer's Society's calls for social care workforce planning to include dementia across England, Wales, and Northern Ireland, setting out why we want and need to see a social care workforce strategy in each nation developed, culminating in a trained workforce equipped with the knowledge and understanding to deliver person-centred care.

# **Keywords**

Social Care, Workforce, Dementia, Training, All-Party Parliamentary Group, Person-centered care.



THE ART OF PLAYFULL CONTACT Caregivers want to make personal contact in which he or she feels truly seen. In this interactive workshop the skills of healthcare clowns can be directly translated to the practice of people with Dementia and come in handy in all kinds of daily situations.

#### Mrs Joscha De Boever

Stichting CliniClowns, Amersfoort, Netherlands

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

The skills of interactive performers, such as Healthcare Clowns, include the ability to read other people and respond to subtle physical and emotional cues. These skills translate directly to the art of making genuine contact with the immediate environment.

Establishing a special moment of contact with people with dementia requires time, attention and playfulness. The creation of contact from play, or vice versa, is a fascinating investigation that takes place non-verbally and sensorially, in which you can ask yourself again and again from wonder: Who are you? What do you feel? What do you do? But also: Who am I? What do I feel? What do I do?

### After this workshop the participants:

- have experienced a methodology in which the quality of the relationshop with the other appears to be essential;
- themselves have practiced the skills and tools needed to (be able to) see people with dementia from an open observation and to adapt their own behavior to the client and his/her environment;
- have experience how inquiry-based play can connect and what it takes to do so;
- have gained knowledge and experience about how play can be used as a tool;

#### and:

- The consciousness of the participant has been raised to be able to step out of the daily (work) routine and communication habit;
- At the end of this training, tensions and barriers to playful contact will have been reduced and one will be inspired to apply this way of making contact in practice.

#### **Keywords**

caregivers dementia, personcentered care, humanization of healthcare, positive health, integrated healthcare, arts and health, informal care, Healthcare clowning, nursing homes



# A scoping review of dementia education programs

**Dr Wendy Hulko**<sup>1</sup>, **Dr Noeman Mirza**<sup>2,1</sup>, Dr Tracy Christianson<sup>1</sup>, Dr Mahtab Nazemi<sup>1</sup>, Ms Alicia Vicic<sup>3</sup>, Ms Emily Bartle<sup>1</sup>

<sup>1</sup>Thompson Rivers University, Kamloops, Canada. <sup>2</sup>University of Windsor, Windsor, Canada. <sup>3</sup>Interior Health, Kamloops, Canada

### **Topic**

**Dementia diagnosis, treatment, care and support:** Importance of cultural context training for carers/provider

### **Abstract**

**Aims:** This scoping review examined literature on dementia education programs (DEPs) for healthcare providers and students to determine the content, duration, participants, delivery mode, attention to culture, and impact of DEPs.

**Methods:** Arksey and O'Malley's (2005) framework for scoping reviews guided the identification, selection, and collation of studies. The search was conducted using the Discover! search engine that includes 63 databases. A total of 25 articles that met the eligibility criteria were included in the review.

**Results:** There were numerous DEPs that varied by frequency and duration, mode of delivery, content, target population, program evaluation measures, and outcomes. Most involved nursing staff and students and took place in Canada, the US, and the UK. The most common delivery mode was a one-time inperson session and a wide variety of topics were covered, both general (e.g., understanding dementia) and specific (e.g., driving, delirium). Twenty different tools were used to measure primarily changes in knowledge and attitudes, with little attention paid to performance and care provision. Three studies focused on culture in terms of race and ethnicity.

**Conclusions:** This scoping review highlights the lack of focus on the impact of DEPs on performance and care provision. It identifies the neglect of culture and culturally safe care in DEPs and the inattention to the perspective and experiences of ethnic minority and racialized communities, particularly the countries of origin of Black, Indigenous, and People of Colour (BIPOC) persons with dementia. The review indicates that DEPs need to meaningfully address culture and culturally safe care in order to respond to the increasing diversity of older adults and health care providers. Future research should focus on program evaluation that attends to the importance of consistent measures, translation of knowledge to practice, and sustainability of DEPs.

### **Keywords**

culture, dementia, education, health care, nursing, program evaluation



Group Homes Australi's Rementia Together retreat- support for people living with dementia and their support partners. equipping with cutting-edge approaches, innovative ways to live well with dementia. The retreat was co-designed by researchers, people living with dementia and their support partners. It includes dementia education, strategies, peer support and psychological debriefing.

### **Mrs Tamar Chayen Krebs**

Group Homes Australia, Sydney, Australia

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

Enabling resilience and minimising the progression of symptoms with an innovative post-diagnostic support programme

Improving the diagnosis rates of conditions that are causing dementia has often been the focus of national Governments, with low attention to the post-diagnostic rehabilitation-focused support which can enable people and their families to be well informed, and resilient, slow down the rate of progression of symptoms and improve functional ability in activities of daily living.

The World Health Organisation Rehabilitation 2030 initiative draws attention to the profound unmet need for rehabilitation worldwide, and highlights the importance of strengthening health systems to provide rehabilitation. WHO recognises the potential for rehabilitation for people living with dementia in their Package of Interventions for Rehabilitation (PIR) resource that contains evidence-based rehabilitation interventions that facilitates the integration of rehabilitation interventions in all service delivery platforms, including dementia care services.

This presentation will describe the 'Rementia Together Program' a five-day post-diagnostic retreat by Group Homes Australia, funded by the Australian Department of Health and Aged Care in order to improve post-diagnostic support for people living with dementia and their support partners.

The program, which was co-designed by researchers and people living with dementia and their Support Partners, is a 5 day residential retreat for couples. It addresses the immediate needs of people living with dementia and their support partners, empowering them for the future and equipping them with cutting-edge, evidence-based cognitive rehabilitation approaches and innovative ways to live well with dementia.

### **Keywords**

Dementia , Innovation, Post Diagnosis, training and education, Care partner



# **Using Guided Imagery to Increase Carer Insight and Empathy**

#### Ms Melora Jackson

Second Wind Dreams, Roswll, USA

### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

Using guided imagery to glimpse into the world of someone living with an progressed dementia can provide insight for carers. Often informal carers have difficulty perceiving how an experience may affect a person with dementia. Learn how to visualize yourself as a person living with dementia, and their potential thoughts and feelings in situations such as personal care routines, celebrations, outings and negotiating new technology. To illustrate, attendees will be taken on a guided imagery journey. Afterward, there will be a discussion about the experience as you are guided to a better understanding of what it is like to walk in the shoes of someone living with dementia and how to provide more empathic, person-centered care. Strategies for improving the experience for the person with dementia will be discussed.

### **Keywords**

empathy, imagery, visualization, carer, strategies, care



# Legally relevant regulations for people with dementia. Examining legal problem areas from an ethical standpoint.

### Ms Lisa Katharina Mayer

The Austrian National Public Health Institute (Gesundheit Österreich GmbH, GÖG), Vienna, Austria

### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

### **Abstract**

In almost every legal system there are areas where people with dementia and their relatives and caregivers are not considered.

For this reason, the Austrian National Public Health Institute conducted scientific research on this topic on behalf of the Federal Ministry of Social Affairs, Health, Care and Consumer Protection within the framework of the strategy "Living well with dementia".

The specific research question in this context was: In which areas of Austrian law are there ethical-based legal gaps for people with dementia? The objective is to assist the client in making strategic decisions based on this legal summary and to facilitate the establishment of a legal framework for individuals with dementia.

As a first step a systematic literature analysis was conducted, to identify international "legal problem areas". Specifically, the aim was to identify those areas in which the rights of people with dementia are not considered or are not taken into account sufficiently. Following this, these identified legal domains were summarized in an overview.

Relevant areas discovered in the course of the systematic research were, for example, driving ability, freedom-restricting measures, housing, participation in research projects, consent to medical treatment, living wills, assisted suicide, and palliative care. As a next step these identified "legal problem areas" were then compared with specific legal regulations in Austria.

Martha Nussbaum's Capability Approach was used as the theoretical framework for this study. Relevant legal regulations were then matched with the capabilities defined by Martha Nussbaum. This reorganized the study and incorporated an ethical perspective.

### **Keywords**

law, ethics, dementia, capability approach





# The economic cost of caring in Ireland: The impact of the Cost of Living Crisis on family carers and taking action to address it

Dr Laura O'Philbin, Dr Diane O'Doherty, Ms Cíara O'Reilly, Ms Clodagh Whelan

The Alzheimer Society of Ireland, Dublin, Ireland

### **Topic**

Dementia as a public health priority: Economics of dementia

### **Abstract**

As the world faces a Cost of Living Crisis, family carers throughout Ireland report significant financial challenges associated with caring for a person with dementia. Over 180,000 people in Ireland are or have been, carers for a family member or partner with dementia, with many more providing support and care in other ways. Caring in Ireland has long been associated with poor health outcomes such as stress, burnout, depression and illness, which may now be intensified by their significant financial difficulties.

Research published by The Alzheimer Society of Ireland (ASI) in collaboration with Family Carers Ireland highlighted that, in 2022, over half of carers had difficulty making ends meet. In 2023, The ASI conducted national research with 72 people with dementia and 597 carers using in-person, telephone and online surveys. Again, half of carers reported difficulty making ends meet, with 9% reporting 'great difficulty' making ends meet. They describe struggling to keep up with mortgage repayments and bills. Others have withdrawn from hobbies and social activities to save money. The rising cost of living goes hand in hand with a rising cost of providing care and support to people with dementia, the effects of which are deeply felt by family carers. They report that financial difficulties are intensifying the stress, burnout and health challenges they already experience.

This presentation will highlight the self-reported economic cost of dementia to family carers in 2023 and the resulting psychosocial impact on carers and people living with dementia. The presentation will include qualitative and quantitative insights into how The ASI transformed this research data into strong advocacy and campaigning tools to lobby the Government for investment in economic and social support for people affected by dementia.

### **Keywords**

Caregivers, economics, health, caring, finance, advocacy



# Peruvian healthcare system readiness for dementia

Dr Maria de los Ángeles Lazo<sup>1</sup>, **Mr Francisco José Tateishi**<sup>1</sup>, **Mrs Miriam Giuliana Lucar**<sup>1</sup>, Dr Antonio Bernabé<sup>1</sup>, Dr Christopher R Butler<sup>2</sup>, Dr María Sofía Cuba<sup>1</sup>, Mr Graham Moore<sup>3</sup>, Mrs Filipa Landeiro<sup>4</sup>, Mrs Maria Kathia Cárdenas<sup>1</sup>, Mr Carlos Vera<sup>1</sup>, Dr Jemma Hawkins<sup>3</sup>

<sup>1</sup>Universidad Peruana Cayetano Heredia, Lima, Peru. <sup>2</sup>Imperial College of London, London, United Kingdom. <sup>3</sup>Cardiff University, Cardiff, United Kingdom. <sup>4</sup>Oxford University, Oxford, United Kingdom

### **Topic**

Dementia as a public health priority: Healthcare system readiness

### **Abstract**

Peru does not have official prevalence data of dementia, however, particular studies indicate that in urban areas 6.85% of the population over 65 years of age has it. Countries such as Peru have significant drivers of the condition such as low socio-economic (monetary poverty 27.5%) and educational levels (21.9% of the population has only primary education). In order to prepare the health system and society in general, it is necessary to start multisectoral studies to understand the complexity of the challenge ahead. The IMPACT project aims to contribute to this.

**Aims:** understand the response of the Peruvian health system to the people with dementia and the family member/s or person supporting them from the perspective of different stakeholders

**Method:** mixed methods approach. Semi-structured interviews with different stakeholders as well as secondary data review to cover 11 themes from the health system (policy environment, financing, infrastructure, service delivery in prevention and management issues, etc.) in three levels (macro, meso and micro) nnd in four different areas of Peru.

**Results:** Limited and heterogeneous response due to the highly fragmented system, lack of political support, first level of care not designed or prepared to deal with dementia cases, reduced amount of specialists, adequate training for health providers attending this group, no guidelines for medical practices and limited research about its characteristics and needs. Also, age stereotypes and lack of awareness about dementia as a medical condition persist in all levels of the health system and society, negatively affecting the effectiveness of its response to their needs.

**Conclusions:** More research is needed, to address stereotypes, increase training for health providers, use technology to facilitate access to services, create models of effective implementation to generate impact on urgent issues and inclusion of preventive and long-term care approaches.

### **Keywords**

Peru, Healthcare system readiness, dementia





# Whether is living longer a benefit?

### Dr Osman Kučuk

Centre for dementia, Sarajevo, Bosnia and Herzegovina

### **Topic**

Dementia as a public health priority: Healthcare system readiness

### **Abstract**

**Introduction:** The current societies in SE Europe are rapidly aging. According to official statistics, the average age of the population is over 43 years. Due to migration, in the total population, lacks people in the 25-44 age group as well as craftmens. The average life expectancy has increased to over 78 years. At the same time, the gap between the period of healthy life and the average length of life has increased.

**Goal:** Identification challenges of people with dementia in SE Europe in the context of meet their needs for health and social protection and putting in connection with challenges of care providers.

**Method:** Analyze of data presented by the renowned experts of the Central and SE Europe on the Business Forum "Innovations in the health and care sectors tailor bridges between Central and SE Europe" in the context of integrated care, palliative and long term care regarding with dementia in decade of healthy aging

Results: Datas shows that societies of the SE Europe are not ready faced with situation they are.

**Conclusion:** We can conclude that the most national systems in the SE Europe do not recognize the principle of integrated care, do not have a defined system of the long-term care or have a significant challenges in implementation, and palliative care connect with oncological patients. Solutions are not simple and have to include many factors that are not only in dependance from the local policy makers and governments but also from entrepreneurial initiatives.

### **Keywords**

dementia, innovations in care area, integrated care, palliative care, long term care, alzheimerbih, demencijaubih, inovacije, demencija, integrisana njega, palijativna njega,



# The Communities that many forget.

Ms Chandrika Kaviraj<sup>1</sup>, Mr Martin Robertson<sup>2</sup>

<sup>1</sup>None, London, United Kingdom. <sup>2</sup>None, Aberdeenshire, United Kingdom

### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

#### **Abstract**

The communities that many forget - Martin Robertson and Chandrika Kaviraj. Experts by Experience. South Asian communitiesDementia is undiscriminating. It can affect people regardless of any protected characteristics, location, faith or no faith. But there are certain groups who are dealing with Dementia diagnosis in the UK who may be dealing with unmet needs. Ethnic communities may not have enough representation in spaces policy and decision-making. How can we meet the needs of people with Dementia? Are measuring and assessment tools appropriate for people in different ethnic backgrounds? Are we singling out some and alienating others - or addressing them at all? Do professionals understand identifiable institutional biases? Is true engagement about being holistic not ethnically profiling. Chandrika KavirajA carer of two elderly parents with different long term conditions and cognitive impairment and a passionate campaigner about health. Rural CommunitiesWhat are the outgoings relating to Agency staff because they can't find the right staff to work in rural areas? Post Diagnosis Support is supposedly guaranteed in Scotland but travel around parts of the country can delay treatment and analysis. What are health authorities doing in education to highlight the benefits of working in health and social care? What are Third Sector organisations and charities campaigning for in the field of Dementia and Alzheimers? https://www.alzheimers.org.uk/research/our-research/research-projects/understanding-needs-andexperiences-people-affected-dementia-rural-areas.Lived Experience has shown disparities between rural areas. Some parts of Scotland are well catered for while others are not.. Martin Robertson.Orca ID; 0000-0002-8899-0365. I live with a rare form of dementia (PCA), so my memory and cognitive functions are not affected. 7 years after diagnosis my IQ has been measured at 120. Co-Chair of EDSIG, a sub committee of ADI looking at the built environment and dementia. I live in rural Aberdeenshire.

### **Keywords**

Dementia, carers, South Asia, rura, isolation



# Integrating old-age mental health care and policy in mental health services and policy in Somaliland. The case study of a conflict setting

**Dr Djibril I Moussa**<sup>1,2</sup>, Mr Abdirahman Sulieman<sup>3</sup>

<sup>1</sup>Amoud University, Borama, Somalia. <sup>2</sup>Global Brain Health Institute, Memory and Aging Center, UCSF, San Francisco, USA. <sup>3</sup>Ministry of Health, Somaliland, Hargeisa, Somalia

### **Topic**

Dementia as a public health priority: Healthcare system readiness

### **Abstract**

The mental health needs of the elderly in the low-and-middle income countries are neglected within the already stigmatized mental health services in the developing countries. In many countries, there are no geriatric psychiatrists or neurologists and even psychiatrists which leaves the burden of old age mental health disorders on the shoulder of family members.

In the last decades, there has a demographic shift with clear epidemiological changes. People are living longer and aging into later adult years. This brings significant public health unmet needs on already stressed mental health services. In many conflict-affected countries like Somaliland, geriatric mental health services are non-existent. Family medicine, internal medicine, neurology, psychiatry, and global mental and brain health will need to hold hands in addressing this global brain health challenge together. Those disorders will include dementia, delirium, depression, and substance use.

Although the World Health Organization plan on brain health, there is a wide need to have wider global health call for brain health diplomacy and advocacy is promising and that it came in the right time, services need to be prioritized for the elderly including inpatient/outpatient and community mental health for the elderly.

In addition to life expectancy, the current public health threats like climate change are also affecting the elderly population through heat waves and other health risks which put already vulnerable old people at increasing risk.

The main challenges facing Somaliland mental health sector is scarce mental health workforce, lack of training in geriatric mental health, brain health and limited prioritization of geriatric psychiatry in mental health package. The opportunity is that the number of psychiatrists, neurologists and family medicine specialists are increasing, and it is the time now to set up multi-disciplinary fashion.

### **Keywords**

Dementia, health policy, Somaliland, mental health policy, health systems



# Advancing dementia research through implementation science

Dr Anita MY Goh<sup>1,2</sup>, Ms Ellen Gaffy<sup>1</sup>, Dr Sanne Peters<sup>2</sup>, Mrs Cathy Roth<sup>3</sup>, Prof Briony Dow<sup>1</sup>

<sup>1</sup>National Ageing Research Institute, Melbourne, Australia. <sup>2</sup>The University of Melbourne, Melbourne, Australia. <sup>3</sup>Professionals with Alzheimers Disease (PALZ), Geelong, Australia

### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

### **Abstract**

**Aims:** Despite the development of numerous evidence-based dementia interventions, translating these interventions into real-world settings remains a significant challenge. Although there are many published studies of dementia interventions, they predominantly focus on whether the intervention is effective in terms of the primary outcomes. Few are studies reporting on the implementation of interventions; that is, examination of the processes, outcomes, and factors influencing sustained change in evidence-based practice. Implementation science, as a multidisciplinary field, has emerged as a crucial field of study for bridging the gap between research and practice in dementia care. This presentation provides an overview of the key themes and findings in the evolving field of dementia implementation science, highlighting its role in improving care outcomes.

**Method/Results:** Key theoretical frameworks will be discussed, including the *Consolidated Framework* for *Implementation Research* and the *Reach, Effectiveness, Adoption, Implementation, and Maintenance* model to examine the complex factors influencing successful adoption and sustainment of dementia care interventions. The presenter also discusses evaluation methods for understanding effectiveness of implementation efforts.

This presentation also presents a Prospero-registered realist review protocol to answer the research questions: Why are some dementia interventions successfully implemented and others not? What works, for whom, how, under what circumstances, and why in the implementation of non-pharmacological interventions designed to improve dementia outcomes? Relevant context, mechanisms, and outcomes will be discussed, as well as recommendations on implementation strategies for future trials, including design and tailoring of strategies to support and improve how interventions are developed and implemented.

**Conclusion(s):** By applying rigorous methodologies, implementation science offers a promising avenue for translating research findings into meaningful improvements in care. It can enhance the quality of life for individuals living with dementia and their caregivers by improving implementation of effective interventions, informing policy, providing evidence on cost-effectiveness and scalability, and influencing decision-makers.

#### **Keywords**

dementia, implementation, implementation science, translation, knowledge translation, implementation strategies, interventions



#### **I12-008**

#### Societal costs of dementia

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#### **Topic**

Dementia as a public health priority: Economics of dementia

#### **Abstract**

**Background:** As diagnosis and treatment rates increase and populations grow and age, additional resources will be needed to meet the global need for dementia care.

**Methods:** We modeled health care spending attributable to dementia and the cost of informal care for people living with dementia from 2000 to 2019. Data were from the Global Burden of Disease 2019 study and from three systematic literature reviews. We projected future costs from 2020 to 2050 based on the past trends in costs, diagnosis rates, and rate of institutionalization.

**Results:** We estimated that in 2019, the direct health care spending attributable to dementia across 204 countries reached \$226.7 billion (95% uncertainty interval [UI] \$122.9–\$367.6) and the cost of informal dementia care was \$831.6 billion (95% UI \$498.9 - \$1,279.6). On average, informal care represents 78.4% (95% UI 70.0% -86.7%) of the total cost of care. We estimated that direct health care spending attributable to dementia will reach \$1.9 trillion (95% UI \$0.8–\$4.4) by 2050, which is estimated to be 11.0% (95% UI 4.3–25.8%) of projected health spending worldwide.

**Conclusion:** These cost estimates underscore the magnitude of health system resources expected to be used to provide care and ensure sufficient and adequate resources for aging populations and their care partners. These results also highlight the important role that informal care plays in provision of care for those with dementia. Incorporating these estimates is critical to fully capture the social cost of dementia.

#### **Keywords**

dementia, Alzheimer's disease, informal cost, caregiving, societal cost



#### **I12-009**

#### Multi-stakeholder shaping of the research agenda for better policy and support for people with dementia and their care partners in future crises – learning from the COVID-19 pandemic

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#### **Topic**

Dementia as a public health priority: COVID-19 and dementia

#### **Abstract**

**Aim:** To ascertain multi-stakeholder research priorities arising from the impact of COVID-19 restrictions on people with dementia living at home and their care partners, and define a strategy to address these priorities in Europe and Latin America to improve policy and support in future crises.

**Methods:** Following consensus-based prioritization methods, we subsequently undertook:

- a systematic literature review to derive a list of topics describing how people with dementia and care partners were impacted by the COVID-19 restrictions;
- an online survey distributed to people with dementia, care partners and health care professionals (HCP) across 5 European and 5 Latin American countries asking respondents to select the 10 most important topics where they felt more research is needed; and an iterative consultancy process involving stakeholders from each country to translate the top 10 priorities into research questions.

**Results:** The literature search identified 70 relevant papers (52 quantitative, 18 qualitative), from which 38 topics were derived. Twenty people with dementia, 79 care partners and 80 HCP completed the survey. The priorities largely overlapped across stakeholder groups and countries. The top 10 priorities included (worries about) accelerated cognitive and physical decline; increased anxiety, depression and loneliness; and increased care burden.

**Conclusion:** The research agenda specifies what future research is needed to inform how people with dementia and care partners can be better supported in times of crises to avoid accelerated decline in health and functioning, and ensure people are better informed of available care and support to avoid stress, anxiety and care burden.

#### **Keywords**

policy, research agenda, priority setting partnership, health system readiness, crisis, COVID-19



#### **I12-010**

## Dementia, the most hit but most ignored during the pandemic, an untold truth in Malaysia

Dr Cecilia Chan

Taylor's University, Kuala Lumpur, Malaysia

#### **Topic**

Dementia as a public health priority: COVID-19 and dementia

#### **Abstract**

Dementia has been "hidden in the shadows" in Malaysia and is one of the most misunderstood and stigmatized health conditions. Our dementia story in Malaysia is often a fear-laden concept and causes us to be terrified when we hear the word dementia and its statistics.

Coronavirus has laid bare the dire state of our current system for all to see so that we all cannot dispute the urgent need to re-evaluate our current system. Until then, Malaysians living with dementia will continue to struggle to get the attention, funding, and skilled support they need to live well and they will continue to be hardest hit in tragic circumstances. People affected by dementia have experienced extreme harm from the restrictions to social contact and reductions in services over this period. Ironically, even when all the pandemic restrictions had been lifted in Malaysia, the healthcare policy on COVID remains unchanged, resulting in disastrous consequences till today.

This will require rethinking, revisioning, and reconstructing diverse living environments and health care approaches if we are to ever achieve a more just, caring, and inclusive society—not only for people living with dementia but for us all. We are in urgent need of collective narratives and improvisations to include people living with dementia in our society and make changes to include them. The existing social as well as health care system is doing the opposite, that is alienating them and isolating them from society.

#### **Keywords**

Dementia, Malaysia, Covid



#### A critical examination and realist review of resource allocation for dementia care in LMIC context: pharmacological solutions vs. human-based care system

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<sup>1</sup>The University of Queensland, Brisbane, Australia. <sup>2</sup>Global Brain Health Institute, Dublin, Ireland. <sup>3</sup>Samvedna Senior Care, Gurugram, India

#### **Topic**

Dementia as a public health priority: Economics of dementia

#### **Abstract**

This study discusses disparities in resource allocation between drug development and workforce investment in dementia care. While the pursuit of pharmaceutical solutions is paramount, it is influenced by a bias towards technological advancements, often favouring those who control capital and technologies. Conversely, workforce development, which is pivotal for dementia, aged care, and disability sectors, remains underfunded despite its potential to redistribute wealth and power.

Using an equity lens, we examine the historical landscape of dementia treatment, including clinical and cost-effectiveness properties, and real-world evidence of implementing dementia drugs in high-income countries (HICs). We discuss recent breakthroughs, focusing on efficacy and safety evidence, as well as the infrastructure requirements for drug delivery. We then explore the underutilisation of human capital in HICs and highlight how this bias is advocated in low- and middle-income countries (LMICs) where human capital is a comparative advantage.

We pose critical questions regarding the implications of "importing" HICs-centric resource allocation policies to LMICs, e.g., in terms of investment budget allocation, healthcare access inequities, and health financing approaches in LMICs. This work highlights how the considerable investment required for developing healthcare infrastructure to support new Alzheimer's disease drug(s) may strain the available resources in LMICs, which instead could have been spent on the development of social care. We ask whether the clinical and economic benefits for patients, families, and the care system outweigh investments in the drug delivery infrastructure and treatment. We highlight that investing in the workforce for non-pharmacological alternatives may offer a superior social return on investment and a more equitable distribution of returns for dementia care in LMIC contexts.

In conclusion, our study advocates for a more balanced approach to addressing the challenges of dementia care, giving equal consideration to both drug development and workforce investment for a more holistic solution.

#### **Keywords**

dementia, care, resource allocation, economics, treatment, technology, workforce, non-pharmacological treatment.



## Building capacity for cost-effective high-quality dementia care in primary care in Canada: Multispecialty Interprofessional Team (MINT) Memory Clinics

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<sup>1</sup>McMaster University, Hamilton, Canada. <sup>2</sup>Geras Centre for Aging Research, Hamilton, Canada

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

Across Canada, MINT (Multi-specialty INterprofessional Team) Memory Clinics are a significant solution to building capacity for cost-effective high-quality dementia care. This presentation will describe this family physician-led and geriatric specialist-supported dementia care model. Evaluation evidence gathered over 15 years will be presented on the effectiveness of this care model from patient and care partner, healthcare provider, and healthcare system perspectives. MINT Clinics offer dementia care provided by highly skilled multidisciplinary teams who have completed standardized nationally accredited training. This model is an efficient, integrated and collaborative approach between primary care, specialist care, and community support services. Building capacity at the primary care level, MINT Clinics have reduced the need for direct referrals to specialists by 90%, reduced wait times for dementia care by 50%, and demonstrated achievement of the quadruple aim of better health outcomes, better patient experience of care, better provider experience of care, and lower costs (by \$51,000 CAD per individual receiving MINT Clinic care as compared to usual care). By delivering timely access to early detection and intervention, the clinics avert crisis events that lead to emergency room visits, hospitalizations and early transition to longterm care. The MINT Clinic model has proven value and scalability, with over 120 MINT Memory Clinics spread across Canada, many in remote and underserved communities and serving equity-deserving groups such as Indigenous, and minority ethnic groups. This care model represents a significant opportunity to address the urgent need to improve the early detection, diagnosis and care for older adults living with dementia.

#### **Keywords**

capacity building, primary care, interprofessional, collaboration, memory clinics



# A New psychosocial goal-setting and manualized support intervention for Independence in Dementia (NIDUS-Family) versus goal-setting and routine care: a single-masked, phase 3, superiority Randomised Controlled Trial

Prof Claudia Cooper<sup>1,2</sup>, Dr Victoria Vickerstaff<sup>3</sup>, Dr Julie Barber<sup>3</sup>, Mrs Rosemary Phillips<sup>4</sup>, Miss Margaret Ogden<sup>5</sup>, Prof Kate Walters<sup>3</sup>, Dr Iain Lang<sup>6</sup>, Dr Penny Rapaport<sup>3</sup>, Dr Vasiliki Orgeta<sup>3</sup>, Prof Kenneth Rockwood<sup>7</sup>, Dr Sara Banks<sup>1</sup>, Dr Maria Palomo<sup>3</sup>, Prof Laurie Butler<sup>8</sup>, Dr Kathryn Lord<sup>9</sup>, Prof Gill Livingston<sup>3</sup>, Prof Sube Banerjee<sup>10</sup>, Prof Jill Manthorpe<sup>11</sup>, Prof Briony Dow<sup>12</sup>, Prof Juanita Hoe<sup>13</sup>, Prof Rachael Hunter<sup>3</sup>, Ms Jessica Budgett<sup>1</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Aims:** Though national guidelines recommend that everyone with a dementia diagnosis receives post-diagnostic support personalised to their needs, few do in practice. Unlike previous interventions that improved individualized, global outcomes (outcomes most personally meaningful across domains) in people with dementia, NIDUS-Family is fully manualized and deliverable by trained and supervised, non-clinical facilitators. We aimed to evaluate whether home-based goal-setting plus NIDUS-Family was more effective than control (goal-setting and routine care) in supporting dyads' attainment of personalised goals aiming for care recipients living as long and well as possible at home.

**Methods:** A two-arm, single-masked, multi-site randomised clinical trial recruiting 302 dyads from community settings. Randomisation was blocked and stratified by site using a 2:1 ratio (intervention: control), with allocations by remote web-based system. NIDUS-Family is tailored to goals that dementia-unpaid/family carer dyads set by selecting modules involving behavioural interventions, carer support, psychoeducation, communication and coping skills, enablement and environmental adaptations. It involves 6-8 video-call/telephone sessions (in-person where Covid-19 restrictions allowed) over 6 months, then telephone follow-ups 2-3 monthly in the next 6 months. Primary outcome was carer-rated Goal Attainment Scaling (GAS) at 12 months. Analyses were intention-to-treat. Trial registration: ISRCTN11425138.

**Results:** From 30.4.20-9.5.21, 204 participants (109 (53.4%) female) were randomised to intervention and 98 (60 (61.2%) female) to control. 247 (82%) completed the primary outcome, which favoured the intervention (mean GAS 58.7 (standard deviation 13.0; n=163) vs 49.0 (14.1; n=84); adjusted difference in means 10.23; 95% Confidence Interval: 5.75-14.71, p<0.001).

**Conclusion:** NIDUS-Family, the first readily scalable intervention for people with dementia that improves individualised, global outcomes should be implemented in health and care services.

#### **Keywords**



## Co-Designing Dementia Care Model with Community Health and Well-being Workers (CHWWs): Navigating the Path to Challenging Inequality and Promoting Inclusiveness

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Background:** CHWWs act as "bridge-builders" between the community and primary care. Inspired by Brazil's Family Health Strategy adopted in 2021, this model involves proactive monthly visits to specific geographic areas regardless of immediate need. CHWWs aim to detect health problems early and address healthcare disparities. Improving early identification and care for individuals with mild cognitive impairment (MCI) and dementia represents a significant public health challenge. Hence, in addition to CHWWs primary roles, we aim to empower CHWWs to create a compassionate and sustainable model for community identification and care, employing a life-course approach.

**Methods:** We conducted a co-design workshop to enhance CHWWs' knowledge, skills, and empathy, aligning dementia care with the unique needs of the community. CHWWs from four general practices in Central London collaboratively shaped care strategies. The workshop included self-reflections, group discussions, dementia education with interactive case-studies, and hands-on cognitive tool experience. Additionally, we conducted an audit to estimate cases within one of the practices.

**Results:** The workshop empowered CHWWs to actively shape dementia care with key outcomes: a) Tailored Training Modules: CHWWs recognized the necessity for training in support, communication, and culturally-sensitive interventions across dementia stages; b) Community Engagement: emphasized awareness programs to reduce stigma and enhance residents' understanding; c) Collaboration with Primary Care Networks: highlighted effective referral pathways for integrated care. In one practice (972 residents), dementia prevalence among those aged 65+ was 2.8% (3/105), with no reported MCI cases. Comparatively, the GP Dementia Registry showed 4% prevalence, NICE reports estimated 7%, and MCI in those aged 50+ was 15.5%. Thus, we estimate CHWWs could potentially identify approximately 4 more individuals with dementia and 42 with MCI.

**Conclusion:** These findings pave the way for innovative community-based primary care to be piloted and adopted for patients with MCI and dementia, ultimately leading to enhanced well-being interventions.

#### **Keywords**

Community Health and Wellbeing Workers, Primary Care Network, Co-Design, Community-based Model, Transformative Primary Care, Early Detection, Dementia, Mild Cognitive Impairment



### Person-Centered and Culturally Humble Dementia Care: Theory and Practice

#### Dr Kumi Oya

The Aging and Disability Resources, Tacoma, USA

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

The number of people with Alzheimer's disease and other dementias is expected to grow globally as the aging population increases around the world. In the U.S., as diverse populations increase, the number of people of color living with dementia will also rise. There is always a good chance that as healthcare professionals, we will most likely serve people who have different cultural backgrounds from our own. To both acknowledge and overcome the history of systemic oppression that includes but is not limited to racism and healthcare disparities, culturally appropriate, humble, and sensitive dementia care is needed and to be implemented in our healthcare field. For this reason, I strongly recommend that we must cultivate and create an environment where dementia care is focused upon person-centeredness and the integrated practice of cultural humility. I would like to introduce and offer dementia care quality principles titled, CHERISH (Compassion, Humility, Empathy, Respect, Intersubjectivity, Spontaneity, Humor) and a care practice model called, LEO (Learn, Engage, Outline) & PAM (Participate, Assess, Modify) for healthcare professionals, discussing the significance of understanding and practicing personcenteredness and cultural humility. Both quality principles and a practice model are based on the idea of examining whom we are serving and who we are as healthcare workers, as well as a people. These are designed to be a supportive tool for healthcare communities to follow and to maintain integrity of our dementia care philosophy/theory and practice to provide good quality of care for all, regardless of race, ethnicity, religion, language, and more.

#### **Keywords**

dementia care, person-centeredness, cultural humility, care quality principles, care practice model



## **Empowering Home-based Dementia Care Model: ARDSI Hyderabad Deccan Chapter**

**Ms Saadiya Hurzuk**<sup>1</sup>, Ms Thashreefa Binth Muhammed Sherif<sup>2</sup>, Dr Najamus Saquib<sup>2,1</sup>, Dr Chandrasekhar Kammammettu<sup>1,2</sup>, Dr Mani Tolety<sup>1</sup>, Mr Shashidhar Komaravolu<sup>1</sup>, Ms Bala Tripura Sundari<sup>1</sup>, Dr Suvarna Alladi<sup>1,3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Background:** There are about 8.8 million people living with dementia in India. With 90% of dementia care occurring at home in LMICs like India, the burden falls heavily on informal caregivers, constituting 50% of the costs. The societal impact is staggering, demanding an expenditure exceeding INR 52,797.2 million (2022). Recognizing the magnitude, the ARDSI Hyderabad chapter developed a care model based on the needs of the community.

**Methods:** With expert dementia professionals at ARDSI Hyderabad Deccan we developed a model which integrates person-centred care in encompassing Cognitive Stimulation Therapy, Functional Rehabilitation, and environment modifications, alongside comprehensive support for family carers, including counselling and education. Our strategy involves prioritizing home-based care that is easily accessible, aiming to assist a significant number. This approach advocates for community-driven solutions.

To bridge this gap of post-diagnostic support, our approach fosters a supportive community through meetings and a WhatsApp support group for carers. These platforms are easily accessible for the majority and facilitate shared experiences, offering solace amid challenges.

To understand the impact of this intervention, we aim to conduct a pre-post-test, in a six-month study involving 20 dementia person-caregiver pairs, we utilize assessments, including Addenbrooke's Cognitive Examination-III and Quality of Life evaluations, to gauge cognitive abilities, behavioural symptoms, and quality of life for the person living with dementia. Caregivers' experiences are measured using the Depression, Anxiety and Stress Scale - 21 Items (DASS-21).

**Conclusion:** Through practical and cost-effective strategies, our approach aims to lessen the carer's impact and significantly reduce the cost of care, this model emphasizes the essential need for comprehensive post-diagnosis interventions and support, presenting a replicable model.

#### **Keywords**

Models of care, Interventions, cost, home-based care, carer support, interventions, person-centred care



## The Effectiveness of Model KEDUSIA-RSM Based on Android against Knowledge, Attitude and Skill's of Familiy, Family Satisfaction, and Cognitive Function for Older People in DKI Jakarta

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

Older adults with dementia can be a burden to the family. Recognizing risk factors for dementia can prevent progressifity. Family nursing interventions through android applications in the digital era are very important to improve family coping skills in caring for elderly with dementia risk factors. The research objective was to obtain an android-based model of KEDUSIA-RSM which is effective for improving family ability, family satisfaction, and cognitive function of the elderly. This study uses an operational research design through 2 stages, namely Stage 1: the development of the integration result model between the preliminary study, literature study and expert consultation and Phase 2: the model trial with the pre and post test design with the control group. The sampling strategy used a multistage cluster with a total sample size of 156, namely 79 families in the intervention group and 77 families in the control group. The results of the research were: 1) Phase I produced application based KEDUSIA-RSM nursing model, handbook for family and its application; 2) Phase II: there is a significant difference in the average ability to care for the family (knowledge, attitudes, skills) and care satisfaction between measurements (before, 2 months and 4 months after the model intervention) in the intervention group (p value <0.05; repeated measure ANOVA) There was a significant difference in the mean cognitive function of the elderly and controlling risk factors for dementia between the two groups in the measurement before and after 4 months (p value <0.05; independent t-test). Conclusion: The KEDUSIA-RSM nursing model is effective in increasing the ability to care for and satisfaction in caring as well as improving cognitive function in the elderly.

#### **Keywords**

ability to care, cognitive function of the elderly, nursing model KEDUSIA-RSM, risk factors for dementia, satisfaction of care



## Dementia SmartCare Villa: A Bush Inspired Grass Root Innovative Model for Dementia Supportive Care in Australia

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Background:** Heathcote Dementia Alliance's (HDA) Dementia SmartCare Villa presents an innovative care model designed to provide respite and support for individuals living with dementia and their formal and informal caregivers. This model combines cutting-edge Artificial Intelligence (Al)safety monitoring technology with creative design and a comforting environment. The primary goal of Dementia SmartCare Villa, targets the well-being and quality of life for both the person with dementia and their caregivers while respecting their privacy and autonomy. We describe this ground breaking approach to dementia care.

Aim: To describe the co-design process and elements of Dementia SmartCare Villa

**Method:** HDA engaged architects who, in consultation with local community members, caregivers and people living with dementia designed the villa. National and international experts and specialists in dementia care, design, colour, environment, Al and assistive technology, and researchers provided input that informed further development of the villa concept. Additionally, HDA board members attended several workshops/training on environmental design, Al and dementia support and care. The internal fit-out involved co-designing fixtures and fittings with local trades and incorporated feedback from in-home care providers, occupational therapists, local caregivers and people living with dementia.

**Results:** Costerfield House, the Dementia SmartCare Villa prototype, was officially launched on 21 September 2023. For the next six months it will serve as a living lab for research and vital information gathering. Following this period, Costerfield House will be used for GreenCare Respite; an initiative providing dementia respite accommodation and inclusive outdoor green space activities for people living with dementia and their caregivers.

**Conclusion:** The Dementia SmartCare Villa is a pioneering model that not only advances dementia care through innovative design and technology but also embodies a commitment to holistic support, research, and community inclusivity. HDA have established a company and social enterprise to commercialise the Dementia SmartCare Villa.

#### **Keywords**

dementia, care, caregivers, artificial intelligence, environment, respite, architecture, design, assistive technology,



#### Improving Quality of Life Throughout the Dementia Continuum

Ms Susannah Dwyer<sup>1</sup>, Mr CHRIS COELHO<sup>2</sup>, Ms Sharon Johnson<sup>3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

For over two decades the Hearthstone Institute has been a leader in non-pharmacological approaches to increasing quality of life for older adults through the "I'm Still Here®" approach. This presentation will provide insight into addressing purposeful living and improving quality of life for all persons living with dementia through Hearthstone's Continuum of Cognitive Health™ (CCH) methodology. The CCH works to create an adaptable approach that can continue to improve the quality of life for these older adults regardless of the severity of their cognitive decline. Utilizing an evidence-based operational and staff education model, this continuum has been designed and adapted to provide the highest levels of specialized support throughout the spectrum of care, including home care, day programs, independent living, assisted living, dementia specific assisted living, skilled nursing, and hospice care.

Since 2017 the CCH model has been successfully implemented at Abe's Garden Community in Nashville, Tennessee. Through innovation and adaptability, the approach has been able to meet the needs in all service lines offered by Abe's Garden, providing consistent support as the cognitive needs of persons with dementia change. Research studies have demonstrated that Hearthstone's I'm Still Here® approach has a statistically significant effect on the following areas: Quality of Life (6% increase), Depression (41% decrease), engagement (28% increase), and anxiety (42% decrease).

This presentation will describe the implementation of the CCH model and provide examples of its use at Abe's Garden and other award-winning Centers of Excellence across the United States.

#### **Keywords**

Quality of Life, Continuum of Care, Senior Living, Innovation



#### Recommendations for Policy and Research for Advance Care Planning in Dementia: International Consensus Recommendations from a Delphi Panel of European Association for Palliative Care Taskforce

Dr Miharu Nakanishi<sup>1,2,3</sup>, Prof Sandra Martins Pereira<sup>4</sup>, Prof Lieve Van den Block<sup>5</sup>, Prof Deborah Parker<sup>6</sup>, Prof Karen Harrison-Dening<sup>7,8</sup>, Prof Paola Di Giulio<sup>9</sup>, Prof Jürgen in der Schmitten<sup>10</sup>, Prof Philip Larkin<sup>11</sup>, Prof Ninoslav Mimica<sup>12,13</sup>, Prof Rebecca L. Sudore<sup>14,15</sup>, Dr Iva Holmerová<sup>16</sup>, Dr Ida Korfage<sup>17</sup>, Dr Jenny T. van der Steen<sup>1,18</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Aims:** Advance care planning (ACP) is growing in importance in the global agenda for dementia care. This study aimed to provide recommendations for both policy initiatives and areas that need further research.

**Method:** The EAPC ACP in Dementia Taskforce conducted a four-round Delphi study between September 2021 and June 2022 with a panel of 107 experts from 33 countries. Delphi panelists were asked to rate their agreement with current policy and regulation statements and to provide comments on what they believe are the most important gaps in research and on policy, in each panelist's country of residence as well as internationally. Conservative criteria for consensus were applied.

**Results:** Consensus was achieved on 11 recommendations regarding advance directive regulation, equity of access, and dementia-inclusive approaches and conversations to express patients' values. Research gaps were identified on a dementia-specific practice model that optimizes engagement and communication with people with impaired capacity and families to support their decision making, while allowing a change of preferences over time. Identified policy gaps included existing health services frameworks that fail to envision dementia-inclusive practice. Policy gaps also included legal validation of ACP and proxy decision making with variations across countries. Guidance by evidence and a call for actions on policy and regulation was recommended.

**Conclusion:** The international Delphi panel achieved consensus on policy recommendations. The research and policy gaps highlight the need for evidence and policy development that will support a dementia-inclusive ACP practice model.

#### **Keywords**

Advance care planning, evidence gaps, health policy, person-centred care



## Down Syndrome and Dementia - an Irish Carers experience of trying to provide appropriate support to / for a family member.

#### Mr David Martin Kieran

Personal, Tipperary, Ireland

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

Statistics suggest that there are 64,000 people living with Dementia in Ireland.

These figures predate the Covid pandemic and the Ukrainian war and therefore, the actual numbers are likely to be grossly understated.

People with Down Syndrome are known to be highly susceptible to dementia and to Alzheimer disease, in particular.

People with Down Syndrome who are affected, typically present with young onset dementia.

MAK was 48 years old when diagnosed with Alzheimer Disease and so the quest to ensure that she lived as well as possible with her changed and changing status began.

This paper outlines personal experiences as follows;

The experience of Diagnosis, post diagnostic challenges, clinical and practical supports.

'Navigating the System' – a Carers experience. The experience of MAK's main carer and brother (himself an experienced Health care professional) in his efforts to ensure that his sister lives well with her progressing condition.

The response of / by existing Service providers.

The absence of appropriate specific supports.

Person centred? 'Opt out clause' – (how labels / protocols allow the system to opt out.

In the absence of appropriate alternatives, this paper documents the response provided by one family committed to ensuring that MAK's experience of her progressing dementia was as person centred as possible.

The author commissioned an OT to prepare a report on the design / refurbishment of a residence, cognisant of the requirements of somebody with the dual challenges of Down Syndrome and Dementia at all possible likely stages of the progression of the condition to include end of life care.

The author extends an invitation to all interested parties to critically review this experience and the consequent functional residential development, as a possible prototype model option of support for the significant cohort of people with Down Syndrome and young onset dementia.

#### **Keywords**

Down Syndrome, Dementia, Support, prototype model,



## U.R.C.A.: An innovative model for the management and support of people with dementia

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<sup>1</sup>Memory Team ETS, bari, Italy. <sup>2</sup>Alzheimer Association, bari, Italy

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

The World Alzheimer Report from 2022 stresses the crucial role of providing a patient-centered basic assistance, to support and help the family in the management process of the neuro-cognitive issue. The association "Memory Team", funded thanks to a national grant from the Department of Youth Policies of the Italian Presidency of the Council of Ministers, aims at promoting both wellbeing and safety of the person with dementia, in the comfort of their homes.

**Aim:** The aim of our ongoing research is to evaluate whether the innovative approach outlined above allows person with dementia and supporter to improve their life quality, prevent and/or effectively deal with any crises stemming from behavioral issues, and support the person care directly at home, without having to resort to first-aid services, hospitalizations, or prescription drugs.

**Methodology:** participants between 65 and 90 years old diagnosed with dementia were selected from 150 families, all resident in Bari (Italy), so to benefit from free assistance and interventions for 12 months. We offer these families:

- 1) on-call emergency service to help manage behavioral crisis directly at home;
- 2) constant support from a dedicated "Case Manager" and original web-app (designed and developed by Memory Team);
- 3) free loans of devices and technologies to ensure the safety of the person with dementia in their own homes.

**Results:** Comparing the results obtained in the pre- and post-intervention assessment, we found a reduction in stress manifestations, a reduction in scores on the scales aimed at investigating the presence of anxiety and depression in people with dementia and an improvement in their quality of life.

**Conclusions:** The data relating to the variables under study demonstrate an important effect of the approach described in reducing behavioral manifestations, improving mood and, above all, quality of life in people with dementia.

#### **Keywords**

patient-centered basic assistance, home support, life quality, on-call emergency service, case manager.



### **Automatic Speech Analysis for Detecting Cognitive Decline of Chinese Older Adults**

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Tongji University, Shanghai, China

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### Abstract

Speech and language disturbances have been observed from the early stages of cognitive decline, and speech analysis has been expected to help as a screening tool for early detection of AD and MCI. Therefore, using ML algorithms to detect cognitive decline has captured wide attention in language and aging studies. Despite large volumes of literature on the applications of ML algorithms on language features for dementia detection, most of the research were based on English speech data, only a limited number of papers focus on Chinese. To develop Chinese model of language analysis for older adults with cognitive decline, we conduct acoustic features (Pitches, Jitter, Shimmer, MFCCs, Formants) and linguistic features (Part-of-speech, Type-token ratio, Information words, Information units) extraction from self-collected natural discourse data from Chinese native speakers. All invited participants in this research completed a picture description task based on the Cookie Theft picture from The Boston Diagnostic Aphasia Examination under the guidance of trained operators. Subjects were 92 older adults (40 male and 52 female) from communities in Shanghai, ranged in age from 53 to 87 (M=69.82, SD=8.82). Older adults were divided into 3 groups including AD, MCI and NC, based on their MoCA-B score. The machine algorithms used in this study include Logistic Regression, Random Forest, Support Vector Machines, Linear Kernel and GNB. The highest accuracy to differentiate NC and AD is 76.79% by SVM, while the highest accuracy to differentiate NC and AD or MCl is 79.35% by linear kernel. We also compared the accuracies of the same model using acoustic and linguistic features for training. The accuracy with linguistic features detection is generally higher than acoustic features in training. Our results suggest the utility and validity of automatic speech analysis is a self-administered and important screening tool for early detection of AD and MCI.

#### **Keywords**

automatic speech analysis, cognitive decline, Chinese, machine learning



## Mediating effect and longitudinal predictive role of choroid plexus in the Alzheimer's disease continuum: A prospective study

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Aims:** To investigate the mediating effect of choroid plexus (ChP)/total intracranial volume (TIV) on the association between CSF biomarkers and cognitive changes, and the associations between baseline ChP volume with clinical progression in patients among Alzheimer's disease (AD) continuum.

**Methods:** Patients who underwent 3.0 T brain MRI between January 1, 2021, and December 31, 2022 were included. Differences in ChP volume and ChP/TIV ratio were compared between patients with MCI and AD dementia at baseline. Mediation analyses were performed to examine the effects of the ChP/TIV ratio on the relationship between CSF biomarkers and cognition. The longitudinal associations between the baseline ChP volume and subsequent changes in neuropsychological characteristics during the follow-up were examined.

**Results:** Initially, 575 participants (110 healthy controls, 247 with MCI, and 218 with AD dementia) were enrolled. Patients with AD presented a greater ChP volume and ChP/TIV than did the rest of them (all P<0.001). The ChP/TIV mediated 21.442% of the association between CSF A $\beta$ 42 levels and MMSE scores after adjustment. After 9.71  $\pm$  3.73 months, the baseline ChP volume was associated with cognitive decline, indicated by decreased MMSE and MoCA scores, and increased ADL scores (all P<0.010). These associations were higher than those between hippocampal or cortical volumes and MMSE, MoCA, and ADL scores.

**Conclusions:** The ChP plays a prominent role in mediating the association between CSF A $\beta$ 42 levels and cognition in patients with AD contunum. ChP can be an independent, convenient, and accurate imaging marker for evaluating AD clinical progression.

#### **Keywords**

Alzheimer's disease, choroid plexus, cerebrospinal fluid,β-amyloid



### Geriatric syndromes in Alzheimer's Disease and Frontotemporal Dementia in Mexico

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### Abstract

**Background:** Many conditions, the frequency of which increases with aging, can be too complicated to be evaluated in a simple disease category. People living with dementia, even in the early stages, have greater vulnerability, which could suggest a higher prevalence of geriatric syndromes. This study aims to know the frequency of geriatric syndromes in people with frontotemporal dementia and Alzheimer's in mild to moderate stages.

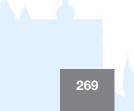
**Methods:** Cross-sectional study, derived from the ReDLat cohort, 87 people were included, of which 24 were typical AD, 11 atypical AD (APP logopenic:1; CBS: 1, PCA: 1, Frontal:1); 19 FTD (Behavioral: 11, Agrammatic: 1, Semantic: 1, ALS: 2, Prodromic: 3) and 33 cognitive unimpaired. A comprehensive geriatric assessment and a standardized cognitive battery were performed.

**Results:** Of the three groups, the typical AD was the oldest and least educated group, while the FTD was the youngest, Age 66.56 vs 64.5 (11.32), education 13.7 vs 14.2 (5.9), Women: 47 (15.3), men: 41 (13.3). The performance in MMSE was lower in amnesic AD (MMSE 20.3/MoCA 14.4), in FTD (MMSE 20.4/MoCA 14.1), the prevalence of geriatric syndromes being higher in the FTD group in falls 73.7% vs AD: 60% vs CU: 24%, dysphagia 26.3% vs AD: 4%, while depressive symptoms were higher in the AD group: GDS: 2.8 vs 2.5, GAD-7: 3.05 vs 1.8. However depression was higher in FTD (57.9%) vs. AD (32%) and CU (21.7%).

**Conclusion:** geriatric syndromes should be known and questioned by all clinicians dealing with dementia patients in their daily practice.

#### **Keywords**

Geriatric syndrome, depresion, fontotempora-dementia, Alzheimer, Mexico





## A cross-sectional study of various memory domains in normal aging population and subjective cognitive decline using PGIMS and Stroop color-word test.

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Background:** Subtle changes in domains of cognition are considered a normal part of the aging process. Still, it is equally important to identify the abnormal neurodegeneration process at an early stage. Subjective cognitive decline (SCD) may be an early sign of Alzheimer's disease (AD), but it is challenging to objectify cognitive impairment in SCD. Hence, we assess memory, executive function, and attention using PGIMS and the Stroop test in younger individuals, normal older adults, and older individuals with subjective cognitive decline to identify the age-related changes in cognitive domains.

**Methodology:** This was a cross-sectional study consisting of 44 SCD individuals (SCD 9 item questionnaire Score>3, CDR:0), 40 cognitively normal older adults (≥ 60 years with no cognitive complaints and CDR:0), and 20 young controls (40-60 years). After collecting detailed history and demographic data, each participant underwent CDR (Clinical Dementia rating) and assessments of various domains of cognition with the PGI Memory scale (PGIMS) and the Stroop test.

**Results:** The patients with SCD had a higher prevalence of mild anxiety and depression. In multinomial regression analysis, we found that older adults (SCD and older control) scored significantly lower than young controls in the verbal retention of dissimilar words test (Co-efficient: -0.34, 95% CI: -0.64 to -0.04). The patients with SCD scored significantly lower in the Stroop color test (Coefficient: -0.19; 95% CI: -0.31 to -0.007) and color word test (co-efficient: -0.11, 95%CI: -0.21 to -0.02), and delayed recall memory in PGIMS (coefficient: -0.62; 95% CI: -1.19 to -0.04).

**Conclusion:** Aging is associated with a decline in verbal retention of dissimilar pairs of words and preserved cognitive flexibility. While, subjective cognitive decline, is characterized by a decline in delayed recall and poor ability to inhibit conflicting responses, could be an early marker of more severe cognitive impairments.

#### **Keywords**

Subjective cognitive Decline, Cognitive assessments, Stroop test, PGIMS



## Development of the Maori Assessment of Neuropsychological Abilities (MANA) for diagnosing dementia in Maori the Indigenous people of Aotearoa New Zealand.

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

Maori, the Indigenous people of New Zealand (NZ) are likely to be over-represented in the diagnosis of Dementia as well as likely to present at a younger age - up to 8 years younger than white New Zealanders.

Three reasons for this over-representation are that (1) Maori are growing older at a faster rate than non-Maori (2) Maori present at a high rate of comorbidities and risk factors such as cardiovascular disease and deprived socio-economic status and (3) there is some evidence that current diagnostic tools used in NZ for diagnosing dementia are culturally bias resulting in false positive diagnose.

A group of Maori clinicians and researchers have developed the Maori Assessment of Neuropsychological Abilities (MANA) for diagnosing dementia in Maori. The MANA comprises of three components: the Wairua (Spirituality) component, The Family Functional assessment component and the Cognitive assessment component.

**Method:** The development of the MANA was guided by the development of the Kimberley Indigenous Cognitive Assessment (KICA).

The structure and context of the questions used in the MANA were developed in close alignment with the qualitative data from over 300 Maori elders who were interviewed on their understandings and experiences of dementia.

**Wairua Component:** Consultation with Maori elders guided those areas of spirituality that were enquired about in the tool. These are: family, genealogy, identity,

**Family/Functional Component:** This component was developed by selecting those domains that featured most in other tools commonly used in NZ to assess functional abilities in the diagnosis of dementia.

**Cognitive Component:** Current measures widely used in NZ were categorised into cognitive domains and weighted. Those domains carrying the most weight were included in the MANA.

Validation: The MANA was validated on 92 people.

#### **Keywords**

Diagnosis, Maori, New Zealand, Culture, Indigenous



#### 'Diagnosing well': Detecting brain health challenges in low resource settings in Greece through a pragmatic primary healthcare e-triage system

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### Abstract

**Background:** Older adults living in low-resource settings cannot easily access brain health services which are mainly tertiary hospital based, if available at all. Here, first experiences of a brain health e-triage system in primary healthcare in Greece are presented.

**Methods:** The INTegRated InterveNtion of pSychogerlatric Care (INTRINSIC) network embodies an e-Health network of tertiary old age mental healthcare services and primary healthcare services for older adults living in low-resource areas in Greece. One of the pillars of the INTRINSIC network is the old-age brain health risk factor surveillance system being a premier system of detection of signs or risk factors that constitute alarm bells (red flags) for the brain health status of service users. This e-Triage system relies on a 21-item questionnaire capturing polypharmacy, falls, weight loss, insomnia, cognitive complaints, traumatic/stressful events, depressive-, anxiety- and cognitive symptoms and hearing loss.

**Results:** 539 older adults living in remote areas have been enrolled in INTRINSIC so far. Cognitive impairment was detected in 55.9% of service users and 59.6 complained about cognitive decline, while depressive symptoms and insomnia were found in approximately 27.8% and 44.5% respectively. Anxiety symptoms and hearing loss were reported by 18.8% and 31.4% of participants. Interestingly, 57% and 27.8 of services users reported stressful events in the past and falls, respectively. Polypharmacy was detected in 41.4% of participants. Red flags led to extensive cognitive and psychiatric diagnostic workup related to them at the respective primary healthcare center and/or to referrals to specialists (e.g. cardio.

**Conclusion:** The brain health e-triage system of INTRINSIC services sheds light on crucial aspects of brain health and paves the way toward individualized interventions in older adults who need them and would not have had access to such services due to living in remote communities of insular or mountain areas in Greece.

#### **Keywords**

Live well, dementia, remote areas



#### Impact of DemClinic: A Qualitative Exploration of Telemedicine-Enabled Cognitive Assessment and Support in Dementia Care

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Background:** Dementia is a neurodegenerative disease with a devastating impact on the person affected and the carers. Dementia contributes significantly to morbidity, disability, and mortality among those who are affected. Around 90% of people with dementia remain undiagnosed. A dearth of memory clinics and mental health professionals makes the scope of early diagnosis and intervention minuscule. People receiving the diagnosis do not have access to quality care, treatment services, and support systems. The usage of virtual platforms for assessment and management of dementia in can alleviate some of the gaps between needs and services. DemClinic is India's first expert-led cognitive assessment platform for the elderly. DemClinic leverages telemedicine technology to increase access to dementia screening, diagnosis, and care. The platform will help in getting timely diagnoses and faster access to experts.

**Aim:** This qualitative study investigates the impact of Demclinic. Through in-depth interviews and thematic analysis, this study explores the experiences and perceptions of individuals who utilized DemClinic services.

**Methodology:** A total of 15 interviews were conducted with family caregivers (n = 15) who attended Demclinic for assessments and post-diagnostic support. Five key themes were identified: (1) Accessibility, (2) Convenience, (3) Guidance and Support, (4) Follow up and adherence, and (5) Risk Management.

**Discussion:** The findings shed light on the positive influence of DemClinic, emphasizing its role in providing timely diagnoses, enhancing accessibility to specialized care, and offering crucial support for caregivers. The study also highlights the effectiveness of DemClinic in addressing the evolving needs of persons with dementia, providing counseling, and post-diagnostic support. Overall, the study underscores the potential of DemClinic as an instrumental tool in improving outcomes and contributing to an enhanced quality of life for both affected individuals and their caregivers.

#### **Keywords**

DemClinic, telemedicine, diagnosis, accessibility, post diagnostic support



## Tablet-based Cognitive Assessment Tool (TabCAT) for detecting cognitive impairments in the elderly during Primary Health Care visits in Southeast Nigeria.

**Dr Chukwuanugo Ogbuagu**<sup>1</sup>, Prof Richard Uwakwe<sup>1</sup>, Prof James Kahn<sup>2</sup>, Dr Ekenechukkwu Ogbuagu<sup>1</sup>, Prof Obiageli Emelumadu<sup>1</sup>, Dr Uzoma Okereke<sup>1</sup>, Dr Irene Okeke<sup>1</sup>, Mr Godswill Chigbo<sup>3</sup>, Ms Collette Goode<sup>2</sup>, Prof Katherine Possin<sup>2</sup>, Prof Bruce Miller<sup>2</sup>, Prof Victor Valcour<sup>2</sup>, Prof Isabel Elaine Allen<sup>2</sup>

<sup>1</sup>Nnamdi Azikiwe University Teaching Hospital, Nnewi, Nigeria. <sup>2</sup>University of California, San Francisco, USA. <sup>3</sup>School of Public Health, University of Port Harcourt, Port Harcourt Rivers State, Nigeria

#### **Topic**

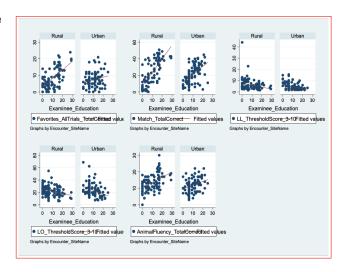
**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Aim:** To examine the useability of a tablet-based cognitive assessment tool in elderly primary healthcare clinic population in southeast Nigeria.

**Method:** A cross-sectional mixed method descriptive study was conducted to evaluate the useability and performance of the TabCAT Brain Health Assessment (TabCAT- BHA) for use among the elderly in primary healthcare settings in southeast Nigeria. The TabCAT-BHA is a 10-minute assessment that includes subtests of memory, executive functions, language generation, and visuospatial skills. We performed a series of ANOVAs that compared rural and urban males and females on each of the 4 tests and evaluated for interactions.

**Result:** A total of 207 subjects participated in the study with the mean age of 64.1±13.9 years. There was a near equal distribution in residence between urban and rural dwellers 50.7%, and 49.3% respectively. Majority (69.7%) were females,



while 30.2% were males, with most being right-handed (96.6%). About half of the participants (51.8%) completed at least a primary level of education. The visuospatial skills (Line length) threshold score amongst the urban participants showed a marked difference with rural female study participants performing better than their male counterparts. This was statistically different (P=0.026). Also, the other component visuospatial skill (line orientation) threshold score among the female urban participants showed huge difference in performance when compared with their male counterparts which was statistically significant (P=0.001). No significant effects were observed between rural and urban males and females on the tests of memory, executive functions, and language generation.

**Conclusion:** With the increasing number of aging populations, and occasional reports of missing elderly persons in SE Nigeria, it underscored the importance of commencing routine cognitive assessment in primary healthcare clinics in low and middle-income countries. There would be need to culturally validate any preferred cognitive assessment tool before deployment for the detection of early cognitive changes.

#### **Keywords**

Cognitive assessment, dementia, elderly, primary healthcare, Nigeria.



## A decade of research excellence in the co-designing and implementation of innovation in rural dementia models of care in Australia

**Prof Irene Darmadi Blackberry**<sup>1,2</sup>, Dr Rachel Winterton<sup>3</sup>, Dr Carmela Leone<sup>3</sup>, Dr Clare Wilding<sup>2</sup>, Dr Tshepo Rasekaba<sup>2</sup>, Dr Sean MacDermott<sup>2</sup>

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#### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

#### **Abstract**

**Background:** The key to dementia care is early diagnosis, and support throughout the journey. The prevalence of dementia is growing disproportionately, with 40% of people living with dementia residing outside of capital cities in what are largely regional and rural settings. Access to dementia care in rural areas is limited due to geographical barriers and a smaller and less specialised care workforce.

**Aims:** To demonstrate lessons and insights gained from co-design and implementation of innovative rural dementia care research, engaging rural communities, people living with dementia and their care partners, and health professionals.

**Method:** A series of co-design and implementation research in rural Australia (2014-2024) using Delphi consultation, pilot feasibility, mixed methods stepped wedge cluster trial, world café, discourse analysis, and implementation science.

Results: Rural communities experience difficulties around service identification, navigation, and access, constrained by workforce shortages and outdated national information. Communities needed help to understand dementia and care partners' experiences. Lack of specialist services and infrastructural challenges were more pronounced in rural settings. However, a strength of rural areas is that people living with dementia are familiar to service providers. A virtual dementia-friendly community facilitated through an integrated website and mobile application, peer-support videoconferencing, and learning hubs was trialled; volunteers were trained to assist care partners to use the application. Cultural attitudes about public and social spaces were explored, to establish genuine rights-based dementia-friendly communities. A directory outlining service pathways was developed to help care partners navigate five different stages along the dementia journey.

**Conclusion:** Although coordination of care typically rests with service providers, our approach emphasises empowering community members to play a critical role in enhancing local dementia care quality. This collaborative effort involving community members, service providers and academia, builds robust capacity to co-design and set up for success sustainable models of rural dementia care.

#### **Keywords**

rural, dementia-friendly, virtual, Al, technology, co-design



#### Inclusivity of Persons Living with Dementia through a Human-Centric Research Design

**Dr May Yeok Koo**, **Ms Wen Lei Ng**, Mr Tommy QUEK, Mr Joe Gui, Mr Madhan Kaliappan, Mr Kar Han Tan, Mr Thomas Ee

Nanyang Polytechnic, Singapore, Singapore

#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

According to a 2015 study, one in ten of people who are 60 years old and above are diagnosed with dementia in Singapore. Additionally, an ongoing study of 818 participants in Singapore has found about 50% of them to have undiagnosed mild cognitive impairment. With the fast ageing population and an alarming number of people being diagnosed with dementia, Singapore is committed to supporting persons living with dementia (PLWD) and their caregivers through various initiatives, with institutes of higher learning such as Nanyang Polytechnic (Singapore) playing an important research and educational role. As such, Nanyang Polytechnic's School of Health & Social Sciences and School of Design & Media collaborated through an interdisciplinary project which focused on inclusivity of PLWD through a human-centric research design. The project was collaborated with and done to aid a voluntary welfare organization's Dementia Day Care Centre by addressing PLWD's difficulties in accessing community premises/services. User pain points were examined through literature reviews, focus group discussions with professional and family caregivers of PLWD and onsite evaluation, using quantitative and qualitative data collection methods, to develop user personas based on unmet needs. A major initiative included designing an inclusive, safe, and accessible wayfinding system for all potential users, considering various environmental factors. The effort highlights design research's significant role in enhancing inclusivity of PLWD and promoting their health and wellbeing.

#### **Keywords**

Human-Centric, Inclusivity, Persons Living with Dementia, Research Design



Using a multi-sectoral collaborative approach to better understand the experience of people impacted by mild Alzheimer's Disease we uncovered a diagnosis dichotomy. We need to do better. We must make diagnosis easier.

**Ms Laura Tamblyn-Watts**<sup>1,2</sup>, Ms Kim Brundrit<sup>3</sup>, Ms Sylvie Grenier<sup>4</sup>, Ms Laveena Kamboj<sup>5</sup>, Dr Linda Lee<sup>6,7,8</sup>, Ms Christina Stergiou-Dayment<sup>9</sup>, Ms Tara Addis<sup>10</sup>

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#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

**Shared Aims:** Co-learning among diverse partners with an aim to gain a deeper appreciation for what a person living with mild Alzheimer's Disease (AD) experiences day to day. We explored what change might have the greatest impact for people living with AD and their care partners to make the experience of diagnosis, disclosure, and treatment easier in Canada.

**Collaborative Approach:** We conducted a series of confidential, qualitative interviews and dialogues with people living with mild AD and care partners. Members of a multi-stakeholder collaboration codesigned the effort to uncover keen insights and attitudes related to the diagnosis, management, and treatment of mild AD.

**Actionable Insights and Implications:** Mild AD diagnosis is being ill conveyed and for the most part unsupported.

A more timely, consistent, and streamlined diagnosis process will decrease apprehension and harm experienced by people living with AD and their care partners.

People diagnosed with mild AD seek deeper disease acumen and affinity. They wish to understand what the possibilities are, what comes next and what is to be expected.

Sharing real life stories and scenarios will help paint a more accurate portrait of AD. Articulating analogous paths where disease modifying therapies already exist may aid closing the gap.

The needs of people living with AD, especially during earlier stages of AD, are under-recognized and often unaddressed by healthcare professionals, family, and friends at the time of diagnosis disclosure.

Developing and disseminating information on how to respond when someone tells you 'I have mild AD' will protect cherished personas.

How the diagnosis is delivered and supported defines how you navigate and experience the healthcare system. Trial and error are frustrating, creating despair where there need not be.

The opportunity to be assessed through a designated memory clinic improves the individual's experience and streamlines the diagnostic process.

#### **Keywords**

Dementia, awareness, attitudes, stigma, diagnosis, partnership, lived experience, well-being, carers, treatment



### The development and implementation of Mobile Dementia Units (MDUs): Athens Alzheimer Association case

**Dr Areti Efthymiou**, Mrs Irene Vamvakari, Dr Eva Ntanasi, Miss Panagiota Zoi, Dr Paraskevi Sakka Athens Alzheimer's Association, Athens, Greece

#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

There are 50 million people living with dementia globally, a number that will increase dramatically in the future due to the increase of life expectancy in both developed and developing countries. According to recent statistics, in Greece 160,000 people suffer from dementia and 280,000 people have mild cognitive impairment. Alzheimer's disease and other forms of dementia cause high healthcare costs as a result of the increased needs for sufferer's treatment and care and support for family. The development and implementation of Mobile Dementia Units (MDUs) could support the role of other dementia services in Greece, usually based in urban areas and assist in dementia treatment and awareness raising.

The aim of MDUs is to create a service delivery network in remote areas to meet the needs of families and people with dementia. In particular the aims include: a) the provision of specialized services at home to people with severe dementia living in remote areas, b) the education and support of their families, c) the creation of a network of services in remote areas with the cooperation of Health Centers, Rural clinics, Hospitals and Municipal social services.

The MDUs are considered a social innovation. Even if mobile units are not new to mental health services in Greece, specialized MDUs are the first time they come to meet the needs of remote areas and of people who are confined to their homes away from services.

The MDUs are funded by the Recovery and Resilience Fund.

#### **Keywords**

dementia services, innovation, home care, mobile unit, awareness



### Partnership approaches: Reducing fire risk for people living with dementia and carers

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#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

2021, saw an estimated 3.3 million people aged 65 years + living alone in the UK and an estimated 944,000 people living with dementia. Notably, Cardiff and the Vale University Health Board were published to have a high number of residences with a diagnosis of dementia (3.2k - 4.3k).

Although, accidental domestic dwelling fires in the UK have decreased, fire Deaths still occur and data for South Wales portrays older people living alone as the most likely to die in a 'house' fire. Therefore, Prevention and intervention is key.

South Wales Fire and Rescue Service (SWFRS) complete approximately 12,000 Home Fire Safety Checks annually, relying heavily on health and social care agencies to refer high risk households. In 2022, Wales introduced the Dementia Care Pathway of Standards to ensure equitable and accessible services for people with dementia. Arguably, there is a strong rationale for teams that support people with dementia to incorporate fire risk as standard procedure during assessments.

With this vision, SWFRS in collaboration with Cardiff and Vale Dementia Learning and Development Team embarked on a project to raise the profile of fire risk, aimed at embedding fire as part of the holistic assessment for people with dementia.

A PDSA cycle was engaged to deliver interactive workforce awareness training, providing an opportunity to discuss actual fire risk concerns and potential interventions to mitigate the risk in relation to the person's level of function and well-being. Referral pathways were explored to emphasise the necessity to work in partnership.

Results have justified the benefits of contextual fire Awareness Training to the extent that it has changed clinical practice, promoted positive risk management, and systemic working that reduces risks in homes. It has also raised the question of improving Fire Data, to capture relatable 'fire and dementia' incidents to inform future work.

#### **Keywords**

Partnership, Fire, Risk, Dementia, Wellbeing





## Thematic analysis of stakeholders' perception on challenges related to caring people living with dementia and on home-based dementia care- a qualitative study

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#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

**Introduction:** Dementia is a devastating experience for the aged population. Just like the rest of the world, India is experiencing population aging and this demographic transition will have a significant impact on old age-related conditions like Dementia. Dementia is a condition that has a huge physical, psychological, social, and economic impact on care partners, their families, and society in large. Firsthand knowledge from the various stakeholders associated with caring for people living with dementia can help in taking measures to meet the challenges associated with the care process.

**Methodology:** The investigators conducted in-depth interviews with care partners, community health workers, and physicians who are associated with the caregiving process. The interviews were then transcribed and analyzed thematically.

**Results and Conclusion:** The research showed the need for community support not only in equipping society to have a better understanding of the condition but also in helping the care partners tackle the burnout states associated with living and managing such an intricate condition. The health of care partners too becomes one of utmost importance to society.

#### **Keywords**

dementia care partner's challenges, thematic analysis, stakeholders in dementia caring, in-depth interviews



## The Impact a Diagnosis of Dementia has on the Person who becomes the carer / supporter

Ms Cíara O'Reilly, Ms Dementia Research Advisory Team

The Alzheimer Society of Ireland, Dublin, Ireland

#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

The Dementia Research Advisory Team (DRAT) is a Person Public Involvement (PPI) panel of current and former family carers and people living with dementia supported by The Alzheimer Society of Ireland. PPI is research with or by patients and the public, rather than for or on them.

Following skills-development workshops in research and facilitation, the DRAT members undertook a new challenge of conducting a research project of their own. They selected and voted on a topic important to them; the "Impact a diagnosis of dementia has on the person who becomes the Supporter / Caregiver."

Members had full authority over the research, and employed a research assistant to support their work. First, a literature review was completed to refine the research question and ensure the work would address gaps in theory and practice. Members decided on the method of data collection and carried out interviews, focus groups and surveys of people affected by dementia. With support from The ASI and their Research Assistant, members analysed the data and decided upon suitable outputs and dissemination methods.

The members of the DRAT wanted to ensure their research translated into practice. Therefore, the results of this work have led to the production of an accessible and informed set of recommendations for healthcare professionals to consider when delivering a diagnosis of dementia (including, the tone of communication during disclosure, signposting and follow-up and considerations for continuity of care.) This supports practice recommendations in the recently published Health Service Executive's Model of Care for Dementia in Ireland. In this presentation, members of the DRAT will share the project results as well as insights from the process, including lessons learned, their experience and how other groups and organisations can replicate this innovative PPI-led work.

#### **Keywords**

Person Public Involvement, PPI



# DEMENTIA AWARENESS THE PILLAR OF CREATING DEMENTIA FRIENDLY COMMUNITIES: THE IMPACT GENERATED BY COMMUNITY, PRIVATE AND PEOPLE PARTNERSHIP IN AWARENESS- CASE STUDY, GHANA.

Mr Venance Dey, Dr Dennis Bortey, Dr Sally Yalley

University of Ghana, Accra, Ghana

#### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

Dementia is a progressive degeneration of the brain and thinking to a degree that it's intellectual functioning is impaired resulting in symptoms such forgetfulness and short-term memory loss, disorientation of place, person and time among others. It is condition

**Prevalence:** About 55million people are estimated to be living with dementia worldwide. An estimated number of 57,000 are living with the condition in Ghana, it's true that Africa including Ghana is aging and it is a thing to celebrate, however, symptoms are mostly stigmatized, therefore awareness and education is key in creating a friendly community that people living with the condition can live a dignified life.

A Case of Lack of Awareness and Its Consequence: In November 2010 a 76 years old woman was burnt to death by one evangelist, a school teacher and two traders. When her son was interviewed by the newspaper (The Daily Graphic), he said; his mother is not a witch however she showed some signs of forgetfulness and old age, Awareness of the disease could have prevented this and many other similar incidents.

Alzheimer's Ghana there engages both local and international partnerships to drive our awareness campaign across the country which is currently changing the narrative.

Targets are sensibly taken to embrace the youth who live with persons with dementia such as High school students, also nursing students who are in the process of training for professional know-how to manage cases after graduation. Churches with averagely high cases whilst not leaving community folks.

Using electronic print and social media, Television and other forms of communication tools, the organisation partners with government agencies, private and public set ups to reach our audience.

#### **Keywords**

Alzheimer'S Ghnana Accra Dementia



## What happens when a busy, enthusiastic, doctor-daughter is suddenly thrown into caring for her estranged father when he was diagnosed with Alzheimer's?

#### **Dr Helena Popovic**

University of Sydney, Sydney, Australia

#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

After unexpectedly finding a box of rivastigmine in the butter compartment of my father's fridge, I started piecing together that he'd been diagnosed with Alzheimer's. Mum had recently passed away with lung cancer and I'd attributed his withdrawal and cognitive decline to grief. Thus began our adventure with dementia. Over the ensuing decade, my all-consuming mission to provide the best care and slow his disease progression led to a discovery I did not expect: dementia need not be a disaster or a dread. Instead, it can be a doorway to creating a healthier brain, stronger body and more fulfilling life. At the age of 78, I bought Dad his first-ever gym membership, his first pet dog and his first iPod. Meticulously working my way through the 12 modifiable risk factors listed in The Lancet in July 2020 (smoking, low education, head injury, type 2 diabetes, hearing loss, hypertension, social isolation, physical inactivity, high BMI, alcohol and air pollution) and adding sleep hygiene, forest bathing, wild salmon, curcumin, B12, raw cacao and volunteering to the mix, our story demonstrates that education is more powerful than medication, and outwitting Alzheimer's is within our reach. Above all, my experience shows that the most significant factor in stabilising Dad's decline was maintaining his sense of meaning, purpose and contribution. It seemed that as long as his brain had a reason to keep functioning, it did. As long as he felt valued and of value, he found it inside himself to keep going. In many ways, my case study of Dad is also a thank you letter to everyone attending ADI 2024. Without their groundbreaking work and exchange of insights, I wouldn't have had the courage to take on the daunting role of caring for my father.

#### **Keywords**

risk, prevention, meaning, purpose, care



### MindCare: Culturally appropriate dementia risk reduction training for Culturally and Linguistically Diverse communities-a protocol.

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Background:** and aims: Dementia is the second leading cause of death in Australia, and the number of people with dementia is expected to reach over one million by 2058. In the absence of a cure, dementia prevention has been identified as a key research priority among culturally and linguistically diverse (CALD) communities.

MindCare aims to improve self-efficacy, health literacy and knowledge of modifiable lifestyle factors through co-production and delivery of an educational dementia prevention program by community peer educators directly to Culturally and Linguistically Diverse (CALD) consumers. The protocol and any available findings will be presented in the current paper.

**Methods:** This study employs a mixed methods design: 1) Co-production of an evidence-based dementia risk reduction program in four languages (Hindi, Arabic, Vietnamese, Greek); 2) user-testing with target communities; 3) Conduct a pilot pragmatic cluster RCT across partner sites across four states in Australia; New South Wales, Victoria, South Australia, and Western Australia, and 4) evaluate implementation success.

**Results:** MindCare is a 3-year project commencing in 2023 which is funded via a national competitive grant scheme specifically focused on consumer engagement in research. We aim to enroll 56-84 CALD consumers and key service providers in the co-design phase, 10-15 CALD consumers in the user testing, and 192-240 CALD consumers in the RCT, and conduct 14-18 interviews with stakeholders to evaluate the implementation success.

**Conclusion:** MindCare is designed to deliver a co-produced, culturally-appropriate and evidence-based dementia prevention program to be delivered by community educators directly to CALD consumers. If effective and well-received, the program will be made freely available to CALD community organisations and will offer a low-cost, high-benefit intervention to reduce the risk of dementia among CALD community members.

#### **Keywords**

Community-led, Diversity, cultural adaptation, dementia risk reduction



#### **I16-003**

## Introducing a brain health education and promotion pathway for patients with mild cognitive impairment diagnosed at a memory service in New Zealand.

Miss Johanna O'Leary<sup>1</sup>, Dr Yu-Min Lin<sup>1</sup>, Dr Sarah Cullum<sup>2,3</sup>

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

Research shows that on average one third of individuals diagnosed with a mild cognitive impairment (MCI) are likely to convert to dementia. They are a group that can be lost to follow up and have difficulties accessing services and support due to not having a dementia diagnosis.

Patients diagnosed with MCI at Te Whatu Ora Counties Manukau memory service in Aotearoa New Zealand (AoNZ) are routinely followed up with a 6-month review, however, until recently, received no other advice or interventions between assessments. Māori and Pacific Islanders in AoNZ are at higher risk of dementia and form half of our patient population. Given the high-risk population, we introduced an MCI pathway based on the FINGERS intervention, which runs from diagnosis until the 6-month reassessment. The pathway involves a goal orientated approach to brain health with patients and family being provided with information in three key areas of nutrition, physical activity, and cognitive stimulation. Each session is 4-6 weeks apart to allow for consolidation of the information provided and time to work towards the goals set at the end of the session. A follow-up phone call between each session provides an opportunity to ask any questions, provide further information/advice.

The pathway was piloted in 2019/2020 and was well received by all participants. It is now embedded in our team's practice. Moving forwards, we would like to transfer the MCI pathway into primary care so that individuals and their families will have access to the same information and service irrespective of who provides their diagnosis. We are also working in partnership with Māori and Pacific partners, tailoring the pathway to individual community needs and promoting rangatiratanga (self-determination).

This presentation will describe the development and implementation of the pathway, and experience with dissemination in Māori and Pacific communities in AoNZ.

#### **Keywords**

Mild cognitive impairment, dementia, brain health, risk-reduction, intervention,





#### **I16-004**

#### Food, cooking and dementia

#### Ms Emily Tan Tan Ong

Dementia Alliance International, Singapore, Singapore. Alzheimer's Disease International, Singapore, Singapore

#### **Topic**

Dementia risk reduction: Dementia and nutrition

#### **Abstract**

Dementia remains largely untreatable, and incurable, making risk reduction and prevention a readily viable option. But risk reduction intervention is equally beneficial for people already diagnosed with dementia because a healthy brain and healthy heart helps to reduce health-related complications while living with dementia. I have been living with young-onset dementia for six years and have incorporated FINGER Intervention to maintain my cognitive health with the aim of slowing down my cognitive decline.

In this presentation, Food, Cooking and Dementia, I would like to share my perspective and experience on dietary changes in my health as well as how food preparation and cooking helps to provide mental stimulation and social engagement. Many people diagnosed with dementia, including myself, shared a common health issue and that is unresolved chronic inflammation. It is a cause of the underlying disease and chronic inflammation also worsens the condition. Research has also shown diets high in food associated with inflammation like deep fried food, may accelerate brain ageing, leading to dementia. This new knowledge changed the way I eat and prepare food. My diet is more towards MIND Diet, which stands for Mediterranean-DASH Intervention for Neurodegenerative Delay. I would like to share how I modified traditional dishes and source local ingredients to make it sustainable and culturally appropriate.

#### **Keywords**

Food, Nutrition, Cooking, Dementia, Risk reduction



#### **I16-005**

### Hormonal contraception and brain health in young women: A scoping review of the evidence

**Dr Sarah Gregory**<sup>1,2</sup>, Dr Laura Booi<sup>3,4</sup>, Ms Natalie Jenkins<sup>5</sup>, Ms Katie Bridgeman<sup>1</sup>, Prof Graciela Muniz-Terrera<sup>6,1</sup>, Dr Francesca R Farina<sup>7,4</sup>

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aim:** Women are more likely to develop Alzheimer's disease and related dementias (ADRD) than men. Explanations of sex differences in dementia incidence have included the women's higher longevity, the influence of sex hormones and key periods such as menopause. By comparison, little attention has been paid to the effects of hormonal contraceptives (HC) on brain health, despite their widespread and long-term use. Our aim was to evaluate the current evidence base for associations between HC use by women and non-binary people in early adulthood and brain health outcomes.

**Method:** We conducted a scoping review of the population (female participants or women, non-binary, and transgender individuals), concept (exposure to HCs) and context (cross-sectional and cohort studies) using EMBASE, Medline and Google Scholar. Keywords included "hormonal contraception" OR "contraception" OR "contraceptive" AND "Alzheimer\*" OR "Brain Health" OR "Dementia". No date limitations were placed, and papers were included if they were in English or Spanish. Data were analysed using narrative synthesis.

**Results:** Eleven papers were identified for inclusion representing participants from the UK, USA, China, South Korea, and Indonesia. Studies included women who were post-menopausal with retrospective data collection. Only one study contemporaneously collected data from participants during HC use. Studies reported associations between HC use and a lower risk of ADRD, particularly Alzheimer's disease (AD), better cognition and larger grey matter volume. Some studies reported stronger associations with longer duration of HC use, however, results were inconsistent. Four studies reported no significant associations between HC use and brain health measures, including brain age on MRI scans and risk of AD.

**Conclusions:** Our findings point towards a possible link between HC and brain health. Further research is needed on young adults taking HCs, including different types, and to explore intersections between sex, gender, race, and ethnicity.

#### **Keywords**

women's health, brain health, hormonal contraception, scoping review



# Reach for the STARS: The My Amazing Brain schools programme.

#### **Mrs Sophie Louise Fraser**

Brain Health Scotland, Edinburgh, United Kingdom

# **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

The onset of the diseases that cause dementia are driven by many factors, some of which we cannot change, such as our family history and genetics, but many of which we can look to affect, such as our lifestyle and certain life choices.

It's never too early for people to start thinking about brain health and establishing good habits early in life can help maintain long term behaviour change. To support young people to have greater understanding of what actions they can take to protect brain health, Brain Health Scotland have developed a new primary schools programme: My Amazing Brain.

My Amazing Brain features a range of free resources for educators of 8-12 year-olds to help children explore all about how to keep their brain healthy. The programme includes a series of animations and hands-on activities, which can be used in a school setting or at other youth groups outside the classroom.

A key concept running throughout is that there are more connections between the cells in our brain than there are stars in our galaxy. The resources therefore speak to children about what healthy actions they can take to keep their stars (brain cells) shining. The acronym STARS is used to cover 5 key areas: S - Spend time with friends and hobbies, T – Tuck in to healthy food, A – Active and healthy, R – Rest and relax, S – Safety, keeping our heads safe.

The My Amazing Brain programme provides an effective and adaptable model which can be applied with minimal cost and training to a variety of educational settings to empower young people to understand and protect their own brain health. The programme is an important tool in the toolkit of primary prevention measures to reduce the incidence of dementia for future generations.

## **Keywords**

Prevention, Schools, brain health



# Myeloproliferative neoplasms and risk of dementia: a populationbased cohort study

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#### **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Aims:** Chronic inflammation and cerebral hypoperfusion may contribute to the development of dementia. We estimated the association between the Philadelphia chromosome negative chronic myeloproliferative neoplasms (MPN) - chronic disorders associated with inflammation, hyperviscosity, and thrombosis - and dementia risk.

**Method:** We identified dementia free persons who were diagnosed with MPN for the first time between 1995-2017 as the MPN cohort (n=9895) and matched them with up to 10 MPN- and dementia-free persons (comparison group; n=95,770) by sex and birth year. Dementia was defined as either a registered dementia diagnosis or having filled a prescription for an anti-dementia drug. The cohorts were followed up to dementia, death, emigration, or December 31, 2018. We estimated the cause-specific hazard ratio and 95% confidence interval (HR, 95%CI) of dementia for persons in the MPN cohorts using the Cox proportional hazards regression model. We repeated the analyses for MPN subtypes - essential thrombocythemia (ET), polycythemia vera (PV), myelofibrosis (MF), and unspecified MPN (CU) - and for subtypes of dementia.

**Results:** Persons with MPN had a 1.15 (95%CI: 1.04–1.27) fold increased risk of all-cause dementia, especially vascular dementia (HR=1.25, 0.96–1.60) and unspecified dementia (HR=1.26, 1.09–1.43). Persons diagnosed with PV (HR=1.36, 1.17–1.55), MF (HR=1.70, 0.83–3.25), or CU (HR=1.38, 1.12–1.65) had an increased risk of dementia. Males with MPN had an increased risk of dementia (HR=1.40, 1.19–1.63 for male; HR=1.02, 0.89–1.15 for female). Younger age at MPN diagnosis was associated with greater dementia risk: the HR was 1.79 (1.33–2.33) for persons diagnosed <65, 1.22 (1.02–1.45) for those diagnosed between 65-74, 1.02 (0.88–1.16) for those diagnosed >=75 years of age.

**Conclusion(s):** Persons with MPN are at increased risk of dementia. Findings support the hypothesis that chronic inflammation and cerebral hypoperfusion contribute to dementia.

#### **Keywords**

chronic inflammation, dementia, myeloproliferative neoplasms, hypoperfusion



# **I16-008**

# Satire and brain health: Piloting a comedy roadshow about dementia risk reduction across England

Dr Laura Marie Booi<sup>1,2</sup>, Dr Kit Green<sup>3</sup>, **Prof Victoria Tischler**<sup>4</sup>, Dr Francesa R Farina<sup>5,2</sup>

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# **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aim:** Brain health education and dementia lifestyle risk reduction awareness measures have never been more needed for the public. Early and effective brain health messaging is necessary to support public health measures to reduce the risk of dementia in later life. Satire has been identified as a viable venue to disseminate information about brain health, especially to under-served populations, and young adults. The aim of this project is to build awareness about brain health and dementia risk reduction among diverse young adult populations through a satirical educational live performance.

**Methods:** The Intergenerational Neurological Education and Prevention Trial (INEPT) is a satirical performance simulating a brain health research study. Central to the immersive experience is a dialogue about brain health and dementia risk reduction, and how best to communicate information about the latest dementia research. The content for INEPT is based on data collected through focus groups and an international survey focused on young adult brain health developed by the Next Generation Brain Health project. INEPT will travel across England to five major cities (Newcastle, Surrey, Leeds, Nottingham, and Birmingham) in November 2023, delivering nine performances in community-based venues. INEPT will be supported by a social media campaign and online resources.

**Results:** Through satirical and comedic approaches, INEPT will deliver complex and emotionally charged information about brain health and dementia risk reduction, making it accessible and entertaining to a wide audience. INEPT will be evaluated via audience engagement, feedback, and social media impact metrics.

**Conclusions:** Disseminating information on how to optimise brain health and reduce future risk of dementia through comedy can facilitate knowledge and awareness building among the general population. Encouraging public discourse around dementia will help to reduce stigma, discrimination, and 'othering' of people living with the condition and their families, creating more inclusive societies for everyone.

#### **Keywords**

Brain health, young adults, awareness, public health, satire, theatre, risk reduction, qualitative research, lifestyle, life course



# Probiotics that ameliorate cognitive impairment through antiinflammation and the progress of a double-blind, randomized, placebo-controlled clinical trial for cognitive improvement

**Prof Kun Ho Lee**<sup>1</sup>, Dr Kyu Yeong Choi<sup>2</sup>, Prof Won-Seok Choi<sup>3</sup>, Prof Junho H Lee<sup>3</sup>, Prof Sejong Oh<sup>3</sup>, Dr Jung Hee Lee<sup>2</sup>

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

Alzheimer's disease (AD) is a progressive neurodegenerative disorder, characterized by memory loss, amyloid accumulation, and neuroinflammation. Recent studies suggest that the microbiota plays a crucial role in modulating neuro-inflammation which in turn influences  $A\beta$  deposition and Alzheimer's disease. In addition, there is some evidence to suggest that probiotics may have a positive effect on cognitive function. In this study, we explored the impact of our probiotics (KL-P301) on anti-inflammation and cognitive enhancement using mouse models. Additionally, we are currently conducting a randomized, double-blinded, placebo-controlled clinical trial to assess the effects of these probiotics on cognitive function.

To investigate the effect of probiotics on anti-inflammation and cognitive function, inflammation-induced mice were orally administrated with probiotics and examined for the Morris water maze test, nitric oxide (NO) assay, and interleukin (IL)- $1\beta$  Elisa assay. For the clinical trial, the participants aged over 60 years were supplemented with probiotics or a placebo for 24 weeks to assess the effects on cognitive function, metabolic status, and anti-inflammation. The participants were randomly divided into two groups treated with either control supplements or a mixture of probiotics.

In mice that received probiotics, the blood levels of NO and IL-1 $\beta$  were significantly decreased, and cognitive evaluation using the Morris water maze test showed significantly improved values in the latency and target quadrant percentages compared to control mice. In our clinical trial, the participants were supplemented with either probiotics or a placebo, and await the tests for cognitive function and biomarkers.

The in vivo study using inflammation-induced mice proves that intake of these probiotics improves cognitive function and memory ability through anti-inflammatory mechanisms. In addition, our ongoing clinical trial awaits the positive effect of probiotics on cognitive function, which expects the potential therapeutic use of our probiotics for cognitive impairment and Alzheimer's disease.

#### **Keywords**

Probiotics, Cognitive impairment, Alzheimer's disease, Anti-inflammation, Gut-brain axis, Clinical trial



# Knowledge of dementia risk factors and multi-level barriers to risk reduction in a remote Peruvian young adult population

Dr Maritza Pintado-Caipa<sup>1</sup>, Dr Laura Booi<sup>1,2</sup>, Dr Francesca R Farina<sup>1,3</sup>

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<sup>3</sup>Northwestern University, Chicago, USA

# **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aim:** Indigenous people, who comprise 6% of the global population, experience significant health disparities. The average life expectancy of indigenous people is as much as 20 years lower than that of their non-Indigenous counterparts. The aim of this study was to investigate knowledge of dementia and multi-level barriers to risk reduction in a remote, predominantly indigenous, Peruvian young adult population.

**Method:** Young adults living in Andean highland, Amazon, and coastal Peruvian regions were recruited to complete a brief survey about dementia knowledge, risk factors, and barriers to risk reduction. Data were analysed using descriptive statistics.

**Results:** Seventy-nine participants completed the survey (53 women, 1 non-binary; mean age =  $29 \pm 6.8$  years). Most participants identified as indigenous or mixed race (81.4%) and lived in rural areas (67.1%). Half of the participants were unemployed and rated their socioeconomic status as low. Nearly one third of participants (30%) did not have electricity or running water (28.6%) in their home. One in five did not have a bathroom (22.8%). Seven participants reported a family history of dementia and 5 had cared for someone with dementia. Nearly half of participants (44.2%) were fearful or worried about developing dementia. On average, participants recognized five of the 12 modifiable risk factors from the 2020 Lancet Commission on Dementia Prevention. However, most participants (71.4%) felt they were not confident about reducing their dementia risk. The biggest barriers to risk reduction were lack of knowledge (72.9%), pre-existing health problems (61%) and lack of money (59.3%). Participants also reported that violence was a major problem in their communities.

**Conclusions:** Young Peruvian adults living in remote areas have moderate knowledge dementia risk factors but identify multiple barriers to risk reduction. Findings are among the first to explore dementia knowledge in Andean highland, Amazon, and coastal regions of Peru.

### **Keywords**

Brain health; young adults; Peru; attitudes; risk reduction; barriers



# Nutrients and Polyphenols-Rich Sorghum Genotypes as Complementary Therapy For Alzheimer's Disease

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#### **Topic**

**Dementia risk reduction:** Dementia and nutrition

#### **Abstract**

**Background:** and Aims: Alzheimer's disease (AD) is a progressive neurodegenerative disorder and most common cause of dementia among older people. AD features gradual memory decline, mild to severe cognitive impairment, eventually total dependence of patients on caregivers. Currently available drugs have not been able to modify AD pathology. This has drawn increasing attention to plant food materials with high nutritional and bioactive constituents as potential complementary therapy for the disease.

**Methods:** Literature search was done using electronic sources. Articles ranked in Scientific Citation Index (SCI) were pooled from Edith Cowan University world search, Pubmed, Springer, Scopus, and Google Scholar databases. The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) was used to filter articles based on the relevance. Recent original research articles were filtered using keywords "Sorghum bicolor", "proximate composition", "polyphenols", "neurodegeneration", "dementia", and "Alzheimer's disease. Abstracts, editorials, and bibliographies of articles not written in English language were excluded. Sorghum genotypes, proximate composition, phenolic profiles, methods of extraction, detection and neuroprotective properties including experimental models were highlighted in tables and figures. This review discussed the mechanisms underlying AD pathology. The nutritional and bioactive constituents of Sorghum bicolor grains were extensively described.

**Results:** Sorghum bicolor grains are widely available cheap source of proteins, fats, crude fibres, biopeptides and polyphenols which promote human health. Only a few studies reported anti-AD activities of sorghum grains. Therefore, the potential pharmacological mechanisms of action were speculated and described including scavenging of reactive oxygen species, inhibition of oxidative stress, anti-acetylcholinesterase activity and modulation of mitophagy.

**Conclusions:** This comprehensive update suggests more innovative studies that will provide critical theoretical details necessary to promote utilization of sorghum grains as a cheap complementary functional food or source of bioactive molecules for AD therapy.

#### **Keywords**

Alzheimer's Disease, Sorghum bicolor, Nutrients, Polyphenols, Therapy



# Development of a Cognitive Training Support Programme for prevention of dementia and cognitive decline in at-risk older adults.

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Background:** The evidence of the beneficial effects of cognitive training on cognitive function and activities of daily living are inconclusive. Poor study quality, different outcome measures, length of training etc. do not allow for robust comparisons of different cognitive training programmes or meta-analyses of combined data. Fairly low adherence to extended cognitive training interventions in clinical trials has been reported.

**Aims:** The aim of developing a novel Cognitive Training Support Programme is to supplement the Computerised Cognitive Training (CCT) intervention component of the multimodal FINGER model, which is adapted to different cultural, regional and economic settings within the WW-FINGERS Network. The main objectives are to improve adherence to the cognitive training through a behaviour change framework and to provide older adults with information about cognitive function, risk factors for cognitive decline and how lifestyle choices, abilities, social engagement and health affect cognitive function.

**Methods:** Six support sessions have been designed covering topics including 1) Introduction to the CCT intervention and instructions for software use, 2) The cognitive domains and tasks included (episodic & working memory, executive function and processing speed), 3) Cognition, ageing and compensatory strategies, 4) Cognitive stimulation and social engagement, 5) Risk factors affecting cognition (sleep, stress, anxiety, depression), 6) Sensory factor deficits affecting cognitive stimulation. Session content will be related to everyday life, with participant reflection on their personal situation and how to take agency for risk reduction through strategies and goal-setting. Feedback aims to enhance motivation and adherence to the CCT.

**Conclusions:** Through interactive presentations on preventing cognitive decline, the programme provides for personal reflection that may enhance capability, opportunity and motivation for behaviour change. This will support adherence to the cognitive training aspect for those participating in lifestyle intervention trials. Evaluation of the effectiveness of the programme will be measured through adherence metrics to the CCT.

#### **Keywords**

Cognitive training, older adults, dementia prevention, risk factors, cognitive decline, cognitive stimulation, cognitive domains, memory, behaviour change, lifestyle interventions



# A study exploring attitudes to risk assessment and management among specialist dementia nurses

#### **Miss Amy Pepper**

Dementia UK, London, United Kingdom

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### Abstract

**Aims:** People living with dementia and their carers may be vulnerable to a number of different risks, including, physical, social, mental health and safeguarding risks. Effective risk assessment and management is, therefore, an important part of the role of a dementia specialist nurse. Despite this, there is no robust framework or assessment tool encompassing all of these risks to support nurses in assessing and managing risk in practice. This study aims to explore levels of confidence and competence among specialist dementia nurses in assessing and managing risks.

**Methods:** A survey design was used to explore how specialist nurses define risk in relation to their clinical practice, their level of confidence and competence in assessing and managing risk, tools and resources currently used in practice. Univariate analysis will be used to examine how nursing background and level of experience is related to confidence and competence in relation to specific risk areas and thematic analysis will be used to examine the open ended responses, and identify overarching themes.

**Results/Conclusion:** The researchers will present their findings, which will help to inform the training and induction needs of specialist dementia nurses, and future research looking at developing a framework for supporting nurses in the assessment and management of risk.

#### **Keywords**

Dementia, risk, nursing, risk assessment



# **I17-005**

# Self-Determination Theory-Based Integrated Creative Art (SDTICA) Program: A Multicenter Randomized Controlled Trial in Nursing Homes for Older Adults with Mild Cognitive Impairment

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

# **Abstract**

**Background:** Previous research has demonstrated the advantages of art therapy in individuals with mild cognitive impairment (MCI), emphasizing the necessity of crafting more immersive and enduring strategies to mitigate cognitive decline. Consequently, this study employs the self-determination theory (SDT) as a theoretical foundation to creatively devise an art-centered intervention for older adults with MCI residing in Chinese nursing homes. The primary objective is to assess the impact of this intervention on cognitive function, mental well-being, and other health-related parameters.

**Method:** A multicenter, two-arm, cluster-randomized controlled trial was conducted in four nursing homes across China. A total of 80 older adults aged ≥ 60 years with MCI were randomly allocated to either the 12-week, 24-session SDTICA program (intervention group) or received usual care (waitlist control group), with two clusters per arm. Primary outcomes and secondary outcomes were assessed at baseline and post-intervention.

**Results:** In the analysis utilizing a mixed-effects model, with P-values adjusted using the Bonferroni method, noteworthy disparities emerged between the two groups regarding our primary outcome measures. Following the intervention, significant distinctions were evident in both MoCA scores and BPNS-competence dimension scores (P < 0.05). Furthermore, within the test group, substantial differences were discerned at various time points for MoCA scores, BPNS-competence dimension scores, AVLT-immediate memory scores, AVLT-short-term memory scores, AVLT-long delayed memory scores, VFT scores, and STT-B scores (P < 0.05). Additionally, a significant interaction effect was observed in both groups for MoCA scores, MMSE scores, BPNS-Competence Dimension scores, ADL scores, QOL-AD scores, and SAS scores concerning group and time (P < 0.05).

**Conclusion:** The SDTICA program has demonstrated its effectiveness in enhancing the cognitive function of individuals with MCI while addressing their fundamental psychological needs. It may serve as a viable non-pharmacological cognitive intervention for individuals with MCI residing in nursing homes and warrants consideration for promotion.

#### **Keywords**

Art; Non-pharmacological intervention; Mild cognitive impairment; Self-determination theory; Cluster-randomised controlled trial; Nursing home



# Causal evidence that herpes zoster vaccination prevents or delays a proportion of dementia cases: a natural experiment in Wales

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

Aims: To determine the causal effect of herpes zoster (HZ) vaccination on new diagnoses of dementia.

**Methods:** In the UK, eligibility for the HZ vaccine (Zostavax) was determined based on an individual's exact date of birth. Those born before September-2-1933 were ineligible (and remained ineligible for life), while those born on or after September-2-1933 were eligible. This natural experiment likely provides causal, as opposed to correlational, evidence because there is no plausible reason why adults born just one week apart should differ systematically from each other. We used a regression discontinuity design in Welsh country-wide data on primary and secondary care encounters, and death certificates. The outcome was a new dementia diagnosis as recorded in any of these data sources.

**Result:** We included 282,541 individuals born between September-1-1925 and August-31-1941. The percentage who received the HZ vaccine increased from 0.01% among those one week too old to be eligible, to 47.2% among those one week younger. Receiving the vaccine reduced the probability of a new dementia diagnosis over seven years by 3.5 percentage points (95% CI: 0.6–7.1, p=0.019), corresponding to a 22.4% relative decrease. To support causality, we show that i) there were no differences in pre-existing conditions or uptake of other preventive interventions across the date-of-birth eligibility cutoff; ii) the HZ vaccine had no effects on any other common causes of morbidity and mortality; and iii) no other interventions used the same date-of-birth eligibility cutoff.

**Conclusions:** Our findings strongly suggest that HZ vaccination slows or prevents the natural history of dementia. Unlike existing studies in this field, this analysis provides causal evidence because individuals who differ in age by just one week are likely exchangeable with each other on both observed and unobserved characteristics, except for a large difference in the probability of receiving the HZ vaccine.

#### **Keywords**

herpes zoster; vaccination; prevention; epidemiology; natural randomization; quasi-experiment; econometrics



# Evaluation of Remotely Supervised Aerobic Training and Resistance Training in Older People with MCI: A Three-arm Randomized Controlled Trial from PACE Project

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# **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** To evaluate the feasibility and effects of remotely supervised aerobic exercise (AE) and resistance exercise (RE) intervention programs in community-dwelling older people with mild cognitive impairment (MCI).

**Methods:** This study is a single-blind, three-arm randomized controlled trial. Community-dwelling older adults with MCI were recruited and equally randomized to AE group, RE group, or control (CON) group. Corresponding interventions were separately delivered to each group with remote supervision. Cognitive functions and physical functions were evaluated at baseline, the third month (T1) and the sixth month (T2). Dropout rates, compliance rates, and adverse events were recorded. Linear mixed effects model was used to evaluate the effects of interventions. Sensitivity analyses were performed after excluding individuals with low compliance rates.

**Results:** Between November 2020 and August 2022, 108 eligible participants were included. And 13.89% of participants dropped out. The median compliance rates in AE group and RE group were respectively 67.31% and 93.27% for the whole intervention period. As for global cognition, linear mixed model showed that ADAs-cog scores in AE group declined by 2.16 points more than that in CON group (p = 0.003) at T1 and 1.62 points more than that in CON group (p = 0.015) at T2, while ADAs-cog score in RE group dropped 1.36 points more than that in CON group (p = 0.049) at T1. For executive function, the time interference in RE group decreased by 11.32 (p = 0.038) seconds more than that in control group, and 12.56 (p = 0.031) seconds more than that in AE group. No other significant effects on cognitive functions were found.

**Conclusions:** Our study confirmed the feasibility and efficacy of remotely supervised AE and RE in older people with MCI. Both AE and RE have positive effects on global cognition, and RE is more conducive to improving executive function.

# **Keywords**

Exercise, Mild Cognitive impairment, Cognitive function, Older people, Randomized Controlled Trial



# Mobile lifestyle intervention using smartphone apps for MCI older adults: a feasibility and acceptability study

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#### **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Objective:** We tested the feasibility of a smartphone application based on the Behavior Change Wheel theory (BCW) and Health Action Process Approach (HAPA) models to support mobile lifestyle interventions in older adults with MCI.

**Methods:** In this prospective single-group pilot study, older adults with MCI (n=48) were tested with the mobile lifestyle intervention "Cognitive Evergreenland" app for 24 weeks. The app was designed to improve cognitive reserve and maintain brain function in MCI patients and included: cognitive stimulation, cognitive training, health education, health monitoring, social support, and functional assessment. As an exploratory trial, it was designed to examine the adherence and engagement of participants in the mobile lifestyle intervention and to analyze changes in health behaviors and cognitive functioning status of MCI patients from baseline (T0) to 12 weeks post-intervention (T1) and 24 weeks post-intervention (T2).

**Results:** The retention rate for the Cognitive Evergreenland Health Management Program was 90.2% (37/41), the mean age of participants was  $70.93 \pm 6.91$ , the mean MoCA score was  $24.51 \pm 2.87$ , and 73.2% were female. During the prescribed 24 weeks of health management, app usage was high, with an average of more than 92% of participants using the applet at least once a week and completing the corresponding health management tasks.In terms of average usage, the most frequently used functional module by participants was cognitive training (95.73%), followed by health education (95.02%).The level of health behaviors among MCI older adults in terms of ability, opportunity, and motivation, increased significantly compared to baseline. In terms of cognitive function, MMSE (Hedges ' g = 0.60) showed significant improvement after the intervention with a moderate effect size.

**Conclusions:** These findings suggest that smartphone applications designed based on theory may help elderly individuals with MCI maintain a healthy lifestyle, and continued use may be beneficial for AD prevention and care.

#### **Keywords**

smartphone, mild cognitive impairment, lifestyle intervention, mHealth



# CLEAR-AI: empowering people living with dementia and their carers to understand and reduce distress.

**Dr Frances Duffy**<sup>1</sup>, Prof Joan Condell<sup>2</sup>, Mr James Gilespie<sup>2</sup>, Dr Kurtis Ashcroft<sup>2</sup>, Ms Leigh Johnston<sup>2</sup>, Dr Siobhan Poulter<sup>2</sup>, Dr Ruth Price<sup>2</sup>, Ms Tara Harkin<sup>2</sup>, Ms Katie McGuinness<sup>2</sup>, Ms Siobhan Casey<sup>3</sup>, Ms Soo Hun<sup>4,5</sup>, Ms Amanda McMurray<sup>2</sup>

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#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

People living with dementia sometimes present with behaviours that carers find difficult to understand and manage. These include aggression, pacing, vocalising, exit-seeking and sexually inappropriate behaviour. They can be present in up to 70% of people living with dementia and often present because of misunderstanding or because of the distress the person experiences trying to cope with the daily challenges of living with their illness. These behaviours increase the risk that a person will move from their home to a care home. CLEAR Dementia Care® helps carers to understand behaviour in the context of the person and their environment, identify unmet needs and respond in ways to reduce distress. We present the pilot of "CLEAR-AI", an artificial intelligence (AI) powered platform that interprets data from a range of connected smart sensors, apps and devices to model the person with dementia's daily routines. Analysis of the data and training the AI model enables the platform to identify the triggers that precede distress episodes and to recognise when episodes occur in the context of previous activities in the day. Using these models, and with CLEAR's assessment as baseline, we can initiate interventions into daily schedules that reduce or mitigate distress where it is likely to arise. The goal is to reduce carer burden and enable the person to live at home with as much independence as possible for as long as possible. Our consortium brings together people living with dementia and their carers, commissioners of digital social care, specialists in dementia care, Al and digital solutions. The co-design approach ensures that we are led by stakeholders' needs to improve quality of life.

#### **Keywords**

distress, agitation, AI, innovation, carers, behaviour, BPSD, unmet need, digital, co-design



# Diagnosis of Alzheimer's disease based on drawing tasks

#### Dr Klaudia Kozlowska

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## **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Introduction:** Alzheimer's disease (AD) is a neurodegenerative condition manifesting in progressive cognitive and behavioral decline. Motor deficits, such as handwriting difficulties, were first reported in patients over a century ago. Since handwriting requires a complex network of skills and functions, previous studies reported significant changes in writing performance in people diagnosed with AD. The 2018 WHO guide emphasizes the importance of research in the dementia action plan by promoting investment in innovative health technologies.

**Aim:** Previous studies on detecting changes in AD patients' handwriting employed features extracted from stylus time series or classification of 2D images with deep learning. In this study, I used a 1D Convolutional Neural Network (CNN) to discriminate handwriting of drawing tasks (horizontal and vertical lines, circles of two diameters, retracing complex shapes) of AD and elderly subjects.

**Methods:** I used the DARWIN (Diagnosis Alzheimer WIth haNdwriting, access: <a href="http://webuser.unicas.">http://webuser.unicas.</a> it/fontanella/darwin/) dataset, including trials from 174 participants. Except for the complex shape drawing, the tasks were repeated four times. Therefore, I split each of them into four parts. I adopted the Leave-One-Out Cross-Validation approach to minimize model bias and prevent overfitting. For each 1-s fragment of a trial, I created three vectors of the stylus: x position, y position, and its tip pressure.

**Results:** The percentages of correctly classified instances are shown in Table 1. The highest accuracy of 69% was achieved for drawing a smaller circle (3 cm in diameter).

**Conclusions:** The results of this study reveal that the classification of drawing time series using 1D CNN may support AD screening with mobile devices.

# TABLE 1. Percentage of correctly classified instances (higher than 51% accuracy for each case).

Horizontal line	Vertical line	Bigger circle	Smaller circle	Complex shape
64	57	58	69	62

#### **Keywords**

Alzheimer's disease, deep learning, drawing



# **Enhancing Clinical Dementia Diagnostics with Multimodal Deep Learning**

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# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Background:** Early and accurate diagnosis of dementia subtypes based on patient reported symptoms and clinical assessment of cognitive impairments is error prone and requires extensive neuropsychological expertise. Computerized Decision Support Systems (CDSS), are crucial for enhancing diagnostic accuracy and throughput, but often struggle with integrating incomplete, multimodal data.

**Methods:** Advances in multimodal, transformer-based model architectures enable the development of advanced CDSSs that address these challenges. Here we present the TeleDemSystem that supports clinicians in answering diagnostic and prognostic questions. We evaluated the system's performance in two scenarios: 1.) differential diagnosis of dementia subtypes based on demographic information, cognitive assessments, and structural brain imaging. 2.) classification of different Alzheimer Disease (AD) stages and risk of progression based on demographic information, fluid-, and imaging-biomarkers.

**Results:** The initial findings for the TeleDem system show superior accuracy in multiclass classification, compared to single-modality classifiers. TeleDem exhibits up to 10% higher accuracy in both evaluated scenarios. In scenario 1, it efficiently discriminates between healthy controls, AD, and three different syndromes of Frontotemporal Lobar Degeneration (FTLD). In scenario 2, it is able to differentiate persons with no cognitive impairment, stable mild cognitive impairment (sMCl), progressive MCl, and AD. Furthermore, the TeleDem system can be used to evaluate the diagnostic importance of individual input parameters by analyzing the parameter-dependent improvement of the task-specific classification accuracy.

**Conclusion:** The TeleDem system represents a significant advancement in the field of diagnostic tools for dementia. Its ability to analyze multimodal data and its robustness against missing data addresses current challenges of CDSS deployed in real-world clinical settings. The system shows promise not only in improving clinical workflows but also in advancing clinical research, identification of novel biomarkers and enhancing patient selection for clinical trials

#### **Keywords**

differential diagnosis, prognostic staging, multimodal deep learning, diagnostic tools, biomarker identification, computerized decision support systems, diagnostic and prognostic Al systems



# **Supporting Self-Management of Medications in Persons Living with Mild Cognitive Impairment**

**Dr Kathleen C Insel**<sup>1</sup>, Dr Wendy A Rogers<sup>2</sup>, Dr Jeannie K Lee<sup>1</sup>, Dr Raksha A Mudar<sup>2</sup>

<sup>1</sup>University of Arizona, Tucson, USA. <sup>2</sup>University of Illinois Urbana Champaign, Champaign, USA

## **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

Mild cognitive impairment (MCI) is characterized by mild impairment in one or more cognitive functions and is associated with an increased risk for failure to take prescribed medications. Hypertension is prevalent among persons with MCI (PwMCI) and nonadherence to medications increases the risk of accelerated cognitive decline through cerebrovascular disease. Adherence is often only 46% or lower among PwMCI. In prior work we developed a theory-based Multifaceted Prospective Memory Intervention (MPMI) to support hypertension medication adherence in cognitively normal older adults. The central goal of MPMI is to change medication-taking from an effortful process dependent on prospective memory to one more dependent on associative processes that are relatively preserved with aging. Intervention strategies included providing education on hypertension and medications, identifying goals for successful medication taking, using implementation intentions to facilitate encoding and storage of the plan for taking medications as intended, providing cues at the time the medication is intended to be taken (reminding at the right time), executing the action of medication taking, and providing a means to monitor if the medication was taken as intended. The intervention resulted in 36% improvement in adherence to a daily prescribed antihypertensive medication. Because adherence declined over 5 months of continued monitoring, we developed a mobile health (mHealth) system called Medication Education, Decision Support, Reminding, and Monitoring (MEDSReM®) to support adherence in cognitively normal older adults and are currently adapting this existing application for PwMCI. No existing studies have evaluated the benefits of mHealth self-management tools to support hypertension medication adherence for PwMCI. We will trace the background of this theory-based intervention and suggest PwMCI can selfmanage medications with less support from caregivers by using prospective memory strategies and by leveraging technology to enhance routine self-management needs, like taking medications.

### **Keywords**

Prospective memory, self-management, hypertension, mHealth, digital therapuetic





Building A.D.A. (the Automated Dementia Assistant). Working with people with dementia and care partners to co-design and co-create a bespoke multimodal wearable product to enhance autonomy, independence and quality of life. Longitude on Dementia Prize winners.

**Dr Lynne Anna Barker**<sup>1</sup>, Dr Anna Zolubak<sup>2</sup>, Prof Sally Fowler-Davis<sup>3</sup>, Dr Abdel-Karim Al-Tamimi<sup>2</sup>, Dr Mohsen Shafizadeh<sup>2</sup>, Mr Alexander William Harcourt Winterbotham<sup>4</sup>, Prof Claire Craig<sup>1</sup>, Mr Andrew Stone<sup>4</sup>, Miss Yoon-Joo Lee<sup>4</sup>

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# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

Our team were recently one of 24 successful teams from 175 global applicants to be awarded first phase funding for the Longitude on Dementia Prize funded by UKRI and Alzheimer's.org. Our idea is a step change from current external assistive aids. We will create an intelligent wearable system (IWS), user-friendly, personalised, smart, unobtrusive, and aesthetically pleasing. The IWS will support multiple self-contained modules that monitor and enable functions, improving independence, autonomy, and quality of life. The IWS will be used to inform diagnosis, monitor progression and tutor the individual through an advanced database embedded into the solution to benefit end-users. Thus, the person can tailor their suite of modules to their needs, and change these as their needs change over time. The product will use AI learning of the user's routine and environment and a coaching element to strengthen any detected limitations.

However, there are several wearable products on the market, particularly in the US and Australia but it is well documented that uptake is often poor for a number of reasons discussed in the presentation. Hence it is vital that new wearable innovations include people living with dementia in the co-design and co-creation of any technological aid from the outset and throughout.

In this presentation we report the use of compassionate and co-design principles to involve those living with dementia and their care partners/family members in the design of A.D.A. We detail the methods of co-design used and areas covered including functions of the product, appearance, wearability, interoperability, user interface, training/coaching elements and other/clinician access to the person's data. In this way we aim to maximise user uptake of A.D.A. at later stages of the technology readiness level (TRL).

#### **Keywords**

Intelligent wearable system, artificial intelligence (Al), multimodal, wearable, autonomy, independence, compassionate design, co-design, co-creation, people with dementia, care partner



# Identification of possible Dementia (Alzheimer's) condition based on formalized handwriting analysis

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#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Aim:** In some cases, the use of modern diagnostic means for Alzheimer's disease (AD) is not available. For instance, in a forensic context or for early warning. Handwriting is one of the most complex human skills. It includes fine motor as well as cognitive activity. Handwriting is sensitive to the changes in the person's condition, including dementia. However, the influence is individual. Therefore, the instrument developed by authors (AD-HS) is based on a complete analysis of a person's handwriting, rather than separate indicating characteristics. The current study aims to validate AD-HS in a group of persons with diagnosed cognitive impairment (CI) or AD.

**Method:** AD-HS includes two linguistic and 39 handwriting characteristics, which were selected based on the literature review, interactions with neurologists, and own statistical studies. From the number of AD-HS characteristics in a sample, we evaluate AD-Indicator (ADI), on a scale from 0 to 1.

**Results:** The validation experiment includes a group of 50 subjects and a control group of 182 persons. The average ADI for the experiment group is 0.46, with a standard deviation of 0.11. The value is significantly higher than the control group's average, which is equal 0.28. Besides, the correlation between ADI and the severity of CI is 0.62.

**Conclusions:** AD-HS demonstrates good psychometric qualities, i.e. objectivity, reliability, and validity, ensuring high distinguishability. That encourages the use of the instrument in different areas, like neurology, sociology, or forensics. This additional indicator could help involved persons and protect them.

#### **Keywords**

Alzheimer's disease, cognitive impairment, handwriting, validation, early screening, formalization, modelling



# Using innovation in technology to engage in dementia care.

#### **Dr Tanya Petrovich**

Dementia Australia, Melbourne, Australia

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

# **Abstract**

Increasing awareness, understanding and improving care practice in dementia can only be achieved through effective engagement with the target audience. This year Dementia Australia released. 'Cutting Edge Technology Applications: Improving the experience of dementia for everyone', capturing the 12 year impact of ground-breaking use of virtual reality, apps and artificial intelligence tools that are changing and improving the support, care practice, knowledge and awareness for all people impacted by dementia.

This presentation will discuss the impact Dementia Australia's tech innovations have had on improving learning experiences. We have used VR to create virtual environments with game technology to create immersive learning experiences, commencing with the Virtual Dementia Experience™ developed in 2013 and has been used to engage professional and family carers in understanding dementia. It also helped to raise awareness through media and award recognition in Australia and Internationally winning the Microsoft Imagine Cup. More recently in 2016 we released the mobile VR experience EDIE, Educational Dementia Immersive Experience, which has won several award for innovation and Simulation Training in Australia. EDIE is now available internationally in 7 countries including New Zealand, Singapore, Czech Republic, and Canada. This experiential learning increases empathy and understanding by allowing carers to see and feel from the perspective of the person living with dementia.

In 2021 using AI we released Talk with Ted an avatar living with dementia, used to engage learners in conversation and learn good communication skills through experiential learning. This application is available internationally online. Most recently we released Ask Annie, an App that delivers microlearning, to support workers available free anywhere in the world. This application helps those supporting the person with dementia to better understand the impact the disease and how they can provide better support and to reduce the behavioural change that may come with dementia.

#### **Keywords**

Innovation, Virtual Reality, Artificial Intelligence, Experiential Learning, Mobile Learning



# A correlation study between lipid and inflammatory profile of patients with Alzheimer disease: moving toward personalized diagnostic approaches.

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# **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

#### **Abstract**

Recently, biomarkers in the plasma of patients with Alzheimer's disease (AD) have gained considerable clinical attention. Several studies have identified potential blood signatures that could aid the development of new diagnostic and therapeutic strategies. For instance, changes in the levels of peripheral amyloid β42 (Aβ42) and tumor necrosis factor alpha (TNFα), and changes in plasma metabolite levels have been demonstrated to predict the progression of systemic processes that affect brain function. We evaluated the plasma levels of A $\beta$ 42 and TNF $\alpha$  and metabolites in 38 patients with AD and 34 healthy elderly (HE) subjects. We analysed the differences in A $\beta$ 42, and TNF $\alpha$  levels using ELISA. Metabolomic analysis was performed to evaluate changes in the vascular components contributing to the disease. The results were interpreted using the Mini-Mental State Examination (MMSE) score. We observed that C26:1- and C28:1lyso-PC levels increased in patients with AD with lower MMSE scores and decreased in patients with higher Aβ42 levels. No plasma metabolites correlated with MMSE scores or Aβ42 levels in patients with high TNFα levels. Changes in the triacylglyceride metabolites were observed in AD patients with higher TNF $\alpha$  levels, but not in those with higher A $\beta$ 42 or lower MMSE scores, suggesting that changes in TNF $\alpha$ levels might be independent of cognitive deterioration in AD patients. This study highlights the possibility of employing a blend of diverse plasma signatures to characterise the specific clinical phenotypes of patient subgroups, which could result in the identification of patients with AD and the creation of personalised treatment plans.

#### **Keywords**

Amyloid beta, TNFa, lipids, metabolomic analysis, peripheral biomarkers



# The genetic architecture of the human anterior commissure and its potential role as biomarker of neurodegeneration

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# **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

#### **Abstract**

**Aim:** To investigate the genetic determinants of the human anterior commissure, a fiber bundle interconnecting the brain's hemispheres. Further, given its presumed role in neurodegeneration, we aim to provide mechanistic insights into neurological conditions that may result from its dysfunction.

**Methods:** Two-stage genome-wide association study, (GWAS) (N=18,828) of the size of the anterior commissure. The discovery sample included seven cohorts (N=7,935) and was meta-analyzed with ten replication cohorts (N=10,893). The size of the anterior commissure was manually derived from magnetic resonance imaging (1.5T or 3T) with at least T1- and T2-weighted sequences. The genetic data was assessed through genotyping using SNP microarrays. We used voxel-based morphometry to determine which regions are connected by the anterior commissure. To provide a functional characterization of the identified variants, we performed a series of in silico experiments, including the study of the spatial expression patterns in human brains, quantitative trait loci (QTL), enrichment analysis and pleiotropy with neurodegenerative diseases.

**Results:** we identified six independent variants at four loci (p-values from 4.1x10-8 to 9.4x10-22). We mapped the loci to probable causal genes involved in axon guidance (*EPHA3* and *SEMA6A*), cognitive disorders (*CTNND2*), and growth factor signaling (*RIT2*). Voxel-based morphometry revealed distinct associations of the variants with connected grey matter regions in the brain. We found enrichment for H3K4me1 peaks (marking enhancer sites), introns, and conserved sequences, as well as cell-type-specific annotations from the central nervous system and cardiovascular system. Furthermore, we identified pleiotropy between genes known to increase risk of neurodegenerative conditions including frontotemporal lobar degeneration gene *TMEM106B*. Variants at this gene have been related to dementia development.

**Conclusion:** these results shed light on the genetic architecture of commissural tracts and establish the size of the anterior commissure as a relevant novel biomarker of neurodegeneration.

#### **Keywords**

neurodegeneration, genetics, anterior commmissure, neuroimaging, genome-wide association study, GWAS, MRI



# 104-week effects of ALZ-801 on plasma and MRI biomarkers and cognition support disease modification in APOE4 carrier early Alzheimer's patients

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#### **Topic**

#### Dementia diagnosis, treatment, care and support: Biomarkers

#### **Abstract**

**AIMS:** ALZ-801 (valiltramiprosate), an oral brain-penetrant amyloid-oligomer inhibitor, is in Phase 3 development in APOE4/4 Early Alzheimer's subjects. A Phase 2 biomarker study evaluated ALZ-801's effects (265mg BID) on plasma AD biomarkers, MRI and clinical outcomes in Early AD APOE4 carriers, powered to detect ≥15% p-tau181 reduction.

**Methods:** This single-arm, 104-week, open-label study enrolled 84 subjects (MMSE 22-30, CDR-G 0.5-1, positive amyloid-PET or CSF biomarkers) who underwent plasma, MRI, and clinical testing every 13 weeks. Dr. Blennow's Laboratory (Sweden) conducted the plasma biomarker assays (Simoa, EuroImmun). Primary and key-secondary endpoints were plasma p-tau181 and hippocampal volume; clinical tests were Rey Auditory-Verbal-Learning-Test (RAVLT), Digit-Symbol-Substitution-Test (DSST) and CDR-SB. Changes-from-baseline on observed data, were analyzed using 2-sided simple t-tests.

**Results:** 84 subjects were enrolled (51% female, age 69 years, MMSE 26.0, 70%/30% had MCI/Mild AD); 70 completed 104-weeks. Plasma p-tau181 showed significant reductions at all timepoints reaching 31%-43% over 52-104 weeks (p=0.045), Aβ42 decreased ~4% over 104 weeks (p=0.042). At 104 weeks, Hippocampus showed 3.6% atrophy that was ~28% less than closely-matched ADNI subjects. RAVLT-total memory and DSST scores improved at 26 weeks, remaining above/at baseline at 104 weeks; 50% and 33% of MCI and Mild AD subjects remained at same CDR-G stage. Cognitive stabilization correlated significantly with decreased MRI hippocampal atrophy (Spearman's r=0.38-0.43, p≤ 0.002); and cortical thinning (r=0.35-0.58, p≤ 0.004). Nausea and appetite loss were the main AE, with no ARIA-E.

**Conclusions:** Over 2 years, oral ALZ-801 reduced plasma p-tau181 and Aβ42 significantly suggesting improved amyloid clearance. Cognition stabilization correlated strongly with lesser brain atrophy, both showing treatment benefit compared to external control. No ARIA-E/vasogenic edema was detected. These results support the disease-modifying effects of ALZ-801 in APOE4 carriers with Early AD.

#### **Keywords**

ALZ-801, valiltramiprosate, amyloid, oligomers, APOE4, plasma biomarkers, plasma p-tau, disease modification, blood-based biomarkers, hippocampus, clinical trial



# Plasma BDNF/irisin ratio associates with cognitive function in older people

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# **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

#### **Abstract**

**Aims:** To examine whether plasma biomarkers and their combination could identify older people with mild cognitive impairment (MCI) from cognitively normal individuals, and to explore their relations with cognitive performance.

**Methods:** We adopted a cross-sectional design, and recruited 250 older adults from community-based health service centers and memory clinics, including 124 participants with MCl and 126 cognitively normal participants. Plasma brain-derived neurotrophic factor (BDNF), irisin and clusterin were measured, and BDNF/irisin ratio was calculated. Global cognition was evaluated. Covariates included age, gender, education, body mass index, exercise habits, smoking and alcohol consumption, disease history, and family history of dementia.

**Results:** Plasma irisin levels, but not BDNF, are significantly different between MCI group and cognitively normal group. Higher irisin concentration associates with an increased probability for MCI (odds ratio (OR): 1.06, 95%CI: (1.02, 1.10)) after adjusting for covariates. By contrast, plasma BDNF levels, but not irisin, is linearly correlated with cognitive performance ( $\beta$  = 0.14, p = 0.033). BDNF/irisin ratios are not only correlated with cognitive performance ( $\beta$ = 0.14, p = 0.036), but also significantly different between the two groups. The risk for MCI decreases by 53% (OR=0.47, 95% CI: (0.23, 0.97)) with each unit increase in BDNF/irisin ratios after adjusting for covariates. Plasma BDNF and irisin concentrations increases with aging, whereas BDNF/irisin ratios remained stable. No significant results of clusterin are observed.

**Conclusions:** Plasma BDNF/irisin ratio is a reliable indicator which not only reflects the odds of the presence of MCI but also directly associates with cognitive performance.

#### **Keywords**

mild cognitive impairment, brain-derived neurotrophic factor, irisin, plasma, old people



# Meaning-making and Well-being of Chinese Working Caregivers of People with Dementia: Implementation of Experience Sampling Method

**Dr Shuangzhou Kevin Chen**, Prof Vivian Lou, Prof Doris Yu the University of Hong Kong, Hong Kong, China

# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Background:** The well-being of Chinese working caregivers of people with dementia (PwD) as the backbone of informal care deserves urgent attention due to constant inflictions of psychological and physical burdens in daily care, work, and personal life. Meaning-making, as an existential method besides various coping approaches, provides valuable support to caregivers' well-being. Existing literature on meaning-making for PwD caregivers predominantly focuses on their caregiving experiences, neglecting work and personal life experiences. A meaning-making choice framework is thus proposed to reflect PwD dementia caregivers' daily experiences and investigate how meaning-making and the care-dyad's relationship affect well-being.

**Methods:** An intensive longitudinal design was implemented to investigate the well-being of 100 working PwD caregivers in Guangzhou, China, from October 2020 to August 2021. The survey consisted of the baseline, the 14-day Experience Sampling Method (ESM), and the follow-up surveys. average well-being scores were calculated to accurately simulate working caregivers' daily experiences. The mediation models and moderated mediation models were adopted to investigate the impact of caregivers' meaning-making choices and dyadic relationships on their well-being.

**Results:** Findings revealed that higher meaning-making levels in care, work, and personal experiences were associated with better hedonic and social well-being. In addition, higher meaningful levels in both care and work aspects led to better well-being than other conditions. Last, better dyadic relationship is critical in improving caregivers' well-being.

**Discussion:** The proposed meaning-making choice model incorporating the dyadic relationship implies that caregivers' well-being can be sustained or improved with high meaning-making levels and/or better dyadic relationships. The meaning-making choice framework indicates that achieving the balance among meaningful care, work and life experiences yields better well-being outcomes. The validated framework gives guidance on meaning-focused interventions and informs theoretical development on meaning-making. The mobile-based ESM design is capable of assessing caregivers' well-being with desirable feasibility, usability, and ecological validity.

# **Keywords**

Meaning-making, Well-being, Chinese Working Dementia Caregivers, Experience Sampling Method



# What can we help you with? - the relationship between information and workload for family members

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aims:** Our goal is to map the care-related information and knowledge of relatives caring for person with dementia (PwD). We examined the prevalence of their mental health conditions, as well as which factors influence their development.

**Methods:** In our research, we conducted online questionnaire data collection (n=191) and personal interviews (n=23) with family members who have been caring for a PwD. The results were processed using descriptive and comparative statistical methods and content analysis. Pearson's correlation and Spearman's correlation were used to compare the variables.

**Results:** The average age of those filling out the questionnaire is 55,32 years, 84,3% of them are women. On average, they spend 10,6 hours a day caring for their relative, for an average of 3,68 years.

One of the reasons for psychological stress (Farran's scale) is the lack of information, a significant, moderately strong positive relationship can be measured (Spearman rho=0.348, p<0.001).

30,5% of responders had knowledge of dementia before care. 75% of caregivers look for answers to their professional questions by browsing the Internet, nearly 60% on social media sites.

Lack of information and emotional burden (Zarit Burden Interview), as well as the appearance of depression symptoms (Beck Depression Inventory) show a moderately strong association, with Spearmans rho=0,592, p<0,001 value.

**Conclusion:** In addition to prevention, the support of family caregivers must begin immediately after the diagnosis of a PwD, as the correlation between lack of information and workload can be demonstrated.

In the future, we consider it necessary to hand over a complex, insightful information booklet to relatives when the first symptoms appear, in which they will also receive information about the disease, care tasks and psychological, mental, physical and financial support.

## **Keywords**

demenciában élőt támogató személy, támogatás hatása, information about dementia



# The Mediating Role of Coping Strategies Between Caregiving Burden and Pre-death Grief among Chinese Dementia Adult Child Caregivers

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### **Topic**

**Support for dementia carers:** Informal carers support – pre, during and post

#### **Abstract**

A growing number of studies have tested the associations between primary stressors and pre-death grief among dementia adult child caregivers, but a few studies have assessed how caregiving burden is associated with pre-death grief, especially among adult child caregivers in mainland China. Whether copings strategies played a mediating role in this correlation was also examined. A convenience sample of 320 dementia adult child caregivers was recruited for the study. Data were collected using the Chinese version of the Marwit-Meuser Caregiver Grief Inventory-Short Form (C-MM-CGI-SF), Burden Scale for Family Caregivers (BSFC), and Ways of Coping Checklist-Revised (WOC). Linear regression and multiple mediation analysis were used to assess the relationship between caregiving burden and pre-death grief, as well as the mediating role of coping strategies. Further analysis was conducted to determine if gender influenced these associations. Results indicated that caregiving burden was positively related to predeath grief and active coping mediated the relationship between them. In the female group, active coping partially mediated the association between caregiving burden and pre-death grief but in the male group, this mediating effect did not exist. The study found evidence supporting the link between caregiving burden and pre-death grief among adult child caregivers of older parents living with dementia in mainland China. Furthermore, the caregiving burden prevented the use of active coping and the decrease of coping increased the perception of pre-death grief. These associations only existed in the female group. Findings of this study emphasized the necessity for health practitioners to provide targeted interventions.

## **Keywords**

dementia, pre-death grief, adult child caregivers, caregiving burden, coping strategies





# ETHHAR, Rebuilding memories through music

Mr Daniel Gadea

ETHHAR, Montevideo, Uruguay

# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

# **Abstract**

ETHHAR is a platform that generates personalized playlists. It works from an input that is the patient's musical and social information that, through an algorithm, generates an output that is the personalized musical selection for that patient.

Alzheimer's disease (AD) is a progressive and irreversible neurodegenerative pathology that causes cognitive impairment and is the main cause of dementia.

The result of musical interventions with music selected by the researcher, usually familiar, with patients diagnosed with Alzheimer's has been studied in numerous investigations.

The results obtained showed improvements in the behavioral, cognitive and memory aspects of the patients.

More than 200 tests were performed on patients with no previous diagnosis or those diagnosed with Parkinson's disease, with the results being more than optimistic.

The objective was to validate whether, with personalized deep musical interventions (IMPP) generated by ETHHAR, the results are more powerful than with interventions with music chosen by the music therapist.

It is understood that the relevant aspects of ETHHAR, such as the personalization of the musical selection and the massiveness of its scope, make it an important tool to complement treatments that aim to improve the cognitive, emotional and behavioral capacity of patients.

The algorithm developed for use in Uruguay will be complemented with the incorporation of Artificial Intelligence to adapt it to any country or region. This process will be incorporated during 2023/2024.

#### **Keywords**

Alzheimer, Music, Memories



# Formation of carer mutual support network after meeting online: lessons learned from a remote dementia support programme delivered by volunteers

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# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aims:** Mutual support network is a valuable asset for informal carers in the community. With the aid of information and communication technology (ICT), it becomes easier to connect carers online. However, little is known about whether these networks can translate into face-to-face interactions and continue for longer term. This study aims to examine the feasibility of a remote dementia support service using ICT for forming carer mutual support network and its impact on carer wellbeing.

**Methods:** The service ('BrainLive') was developed and piloted with people living with dementia and their informal carers in Hong Kong. Informal carers, in groups of three, participated in an online multicomponent carer support group hosted by a trained young-old volunteer (age > 50) for 9 months. Using mixed methods approach, data were collected through pre- and post-assessments, and post-programme in-depth interviews.

**Results:** Among 180 informal carers (78% women; age =  $63.0\pm13.5$ ; education =  $11.4\pm4.9$  years), 70% met face-to-face for social gatherings when the pandemic was less severe. For their long-term connection, 89% kept in contact after service completion. Most of the carers stayed in the chat group they formed with the volunteer and the other two families. They would share useful resources and information, and continued to meet online occasionally. Carers also showed improvements in their health-related quality of life (mean difference =  $0.027\pm0.16$ ), p<.05) in 9 months, level of distress caused by BPSD (mean difference =  $1.54\pm6.68$ , p<.01), and their ICT literacy (mean difference =  $3.01\pm8.78$ , p<.001) in 9 weeks.

**Conclusion:** With optimal support, sufficient service duration, and aligned expectations, support network formed online can be translated into carer's daily lives and sustained beyond time-limited intervention. Following the productive ageing approach, young-old volunteers might assume a larger role in forming carer support networks in the community.

#### **Keywords**

Mutual support network, online intervention, volunteer, carer support group, community





# **Podcasting for our Peers**

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# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Background:** The Dementia Carers Campaign Network (DCCN), supported by The Alzheimer Society of Ireland, is an advocacy group of carers who support loved ones with dementia. The group aims to be a voice of and for dementia carers in Ireland, and to raise awareness of issues affecting families living with dementia. (The DCCN is not a support group but is a supportive environment. We do not offer formal carer training, but we work on building advocates' capacity).

Since its establishment in 2013, members participate in research, speak at conferences and events, provide feedback on national dementia policy and campaigns, meet with political representatives, and take part in awareness raising activities. The group also influences the work of The Alzheimer Society of Ireland.

**Content:** The DCCN was formed to facilitate the inclusion of the dementia carers' voice in public discourse. The DCCN has created and recorded a podcast. The rationale for a podcast was as a way to reach new audiences. The purpose of the podcast is to share information, raise awareness, and reduce stigma – showing family carers that they are not alone; that others are struggling or have struggled with the realities of caring.

The podcast series is called DemTalks – Our Stories, Our Voices. The podcast series has seven episodes, and the topics have been chosen by the DCCN members to cover a wide range of subjects. Each episode will feature a family carer/DCCN member, an interview with a carer in the public eye, and an expert/professional on the topic.

The presenters will share the details of the podcast including how the topics were chosen, how we found experts/professionals to take part in the podcast, how the podcast has been received and the lessons learned from creating the podcast.

# **Keywords**

Podcast, Carers



# Study on the influence of chronic stress on the performance of the caregiver role of relatives of older adults diagnosed with Alzheimer's in El Salvador.

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#### **Topic**

Support for dementia carers: Informal carers support - pre, during and post

#### **Abstract**

The objective of the research was to determine the influence of Burnout Syndrome on the performance of the caregiver role in caregivers of older adults with Alzheimer's at the Arce Polyclinic Hospital of the Salvadoran Social Security Institute. The study was mixed, with a transversal approach and correlational and analytical scope. It focused on informal caregivers of older adults whose relatives are members of the Alzheimer's Family Association of El Salvador and receive care at the Arce Polyclinic Hospital of the Salvadoran Social Security Institute in outpatient consultation. 62 caregivers participated, of which 61 were women and 1 was a man. The results highlight that the participants provide comfort care effectively and efficiently, covering needs in a timely manner and guaranteeing safety and continuity, with the prevention of accidents and risks. However, a high prevalence of Burnout Syndrome was found in three of the four dimensions analyzed. Despite this, in the cultural context, the participants show a strong religious conviction that provides them with strength and a solid faith in a compensatory providence.lt was concluded that Burnout Syndrome influences the performance of the caregiver role in caregivers of older adults with Alzheimer's at the Arce Polyclinic Hospital of the Salvadoran Social Security Institute. Based on the results, the creation of a comprehensive social intervention program aimed at providing support to informal caregivers of older adults with Alzheimer's who are part of the national public system has been proposed. The implementation of the program aims to promote self-care and both the physical and mental well-being of these caregivers.

#### **Keywords**

Informal Caregivers, Burnout, Older Adults, Alzheimer's Dementia, Role Performance.



# A Feasibility and Adaptation study of a physical activity mobile application, "CareFit" for informal carers of people with dementia

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# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Background:** Physical activity is a critical component of both wellbeing and preventative health, reducing the risk of both chronic mental and physical conditions. National level survey data suggests that 81% of informal (unpaid) carers would like to do more regular physical activity. The objective of this work is to expand and personalise a cross-platform digital health app, designed to support regular physical activity over an 8-week period, and evaluate its implementation potential for carers of people with dementia.

**Methods:** The study is a mixed methods codesign, development and evaluation of a cross platform digital health app to support physical activity for unpaid dementia carers. The first phase included iterative design sprints to repurpose an initial prototype for widespread use. The second phase released the app across Scotland on the Apple and Google stores, to be tested by up to 50 carers, and evaluate engagement with up to 40 professionals. Partnerships and codesign included a wide range of stakeholders including health and social care partnerships, carers of people with dementia, and charities. We explored implementation of CareFit, guided by the RE-AIM framework across Reach, Effectiveness, Adoption, Implementation and Maintenance.

**Results:** Study processes and outcomes were evaluated using mixed methods. The barriers and enablers for professional staff to signpost CareFit were assessed through qualitative interviews or focus groups and round stakeholder meetings. The extent to which CareFit can add value for carers was examined through exploring app data, pre-post questionnaire responses, alongside qualitative work including interviews and focus groups.

**Conclusions:** Results from this innovative study will contribute new knowledge in: (i) suitable pathways to identify and support carers through digital innovations; (ii) future design of definitive studies in carer populations alongside; and (iii) an improved understanding of the reach, effectiveness, adoption, implementation and maintenance across a range of key stakeholders.

### **Keywords**

carers, dementia, physical activity, sedentary, behavioural change, cross platform app



# Use of community health workers in screening for cognitive impairment among older persons in Wakiso district, Uganda.

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# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Background:** In Uganda, cognitive impairment in older persons aged ≥60 years is often undiagnosed due to inadequate appreciation of the condition compounded with limitations of trained human resource able to conduct appropriate cognitive evaluations. Use of Community Health Workers (CHWs) can be an important link for older persons to the health facilities where they can receive adequate evaluations and interventions for cognitive challenges. The aim of the study was to assess the feasibility of screening for cognitive impairment among older persons and referral by CHWs in Wakiso district, Uganda.

Methods: This was a sequential explanatory study. The CHWs received a one-day training on causes, signs and symptoms, and management of cognitive impairment and screened older persons ≥60 years for cognitive impairment using the Alzheimer's Disease scale 8 (AD8). Psychiatric clinical officers (PCOs) administered the AD8 and the Mini-Mental State Examination to the older persons after assessment by the CHWs who then referred them for appropriate clinical care. We conducted Kappa statistic for agreement between the CHWs and PCOs and compared raw scores of the CHWs to Experts scores using Bland Altman and pair plots and corresponding analyses.

**Results:** We collected data from 385 older persons. We involved 12 CHWs and 75% were females, majority were married (58.3%) with at least a secondary education (66.7%). There was 96.4% (CI 94.5% to 98.2%) agreement between PCOs and CHWs in identifying cognitive impairment. Of the 58 identified to have cognitive impairment by the CHWs, 93.1% were referred for care. The average difference between the score of the expert and that of the CHW was -0.042 with a 95% CI of -1.335 to 1.252. Corresponding Bland Altman and pair plots showed high agreement between the measurements

**Conclusion:** CHWs can be trained to identify and refer older persons with cognitive impairment in the communities.

#### **Keywords**

Cognitive impairment, older persons, Community Health Workers





# Family carers of people living with dementia in Brazil

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# **Topic**

Support for dementia carers: Informal carers support – pre, during and post

### Abstract

**Aim:** We sought to characterize family cares (people without formal employment contracts who are not paid for care delivery) of people living with dementia in Brazil and explore associations with potentially relevant factors of increased hours spent on care.

**Methods:** This is a cross-sectional study of the ReNaDe project, funded by the Program PROADI-SUS in Brazil. We carried out domiciliary interviews with carers of people with dementia over the five Brazilian geographical regions. We collected data through a questionnaire regarding carers' sociodemographic characteristics, resource utilization, impacts of caring, and mental health. We used the following daily life activities measures: Basic Activities of Daily Life (BADL), Instrumental Activities of Daily Life (IADL), and Supervision (referring to preventing dangerous events). We conducted descriptive and linear regression analyses to assess which variables were associated with the number of hours dedicated to daily life activities.

**Results:** Our sample comprised 117 family carers, most women (85.5%), mean age of 57.9 (13.1). They were mainly the offspring (59.8%) of a person with dementia, had been the carer for 2-3 years (35%), and presented care-related overload (72.6%). Overall, the time spent per day caring for a person with dementia encompasses an average of 3.09 ( $\pm$ 2.65) hours on BADL, 4.46 ( $\pm$ 2.33) hours on IADL, and 6.58 ( $\pm$ 6.21) hours on Supervision. Later stages of the disease increased the number of hours on BADL. Being a woman and feeling the impacts of caring increased the hours dedicated to IADL. More advanced stages of dementia, being a woman, feeling the effects of caring, and having better mental health increased the number of hours dedicated to Supervision.

**Conclusions:** Dementia family carers in Brazil are mainly women needing health and social support to deal with the many hours dedicated to the daily care of people with dementia.

#### **Keywords**

family carers, daily life activities, dementia care, Brazil.



Loving Till You're Broke - The Financial Hardships Faced By Dementia Caregivers Who Give Up Their Full-Time Jobs to Care for Their Loved Ones with Dementia. Examining the sufficiency of the Mental Capacity Act 2008 in Singapore and Existing Social Policies in Financially Supporting Caregivers.

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

One of the possibly greatest challenges facing dementia carers is financial hardship, this happens when the family dementia carer is unable to gain full-time employment. Often, the carer suffers economic loss in this period of time of caring, supporting themselves using their own savings if there is no financial support from the government or their family. The difficulties for the carers to return to the workforce and their careers after the end of their caregiving duties could also be a challenge without adequate training. This could possibly impact the carer's retirement finances and quality of life especially if they have to return to work at a later age for survival.

The Mental Capacity Act 2005 in England and Wales and the Mental Capacity Act 2008 in Singapore are both in essence, similar because of the adoption of similar principles in relation to the protection of the rights, dignity, and autonomy of the person without mental capacity, the difference is that the Singapore MCA specifically prohibits lay deputies or donees, who are often the main carer themselves, from remuneration for their time spent in caring.

What more can be done to better support the financial needs of dementia carers? How can governmental policies, and legal frameworks be better to allow dementia carers not to be left in a worse-off financial position when their caring duties end?

#### **Keywords**

Financial Support, Deputies, Donees, Dementia Caregivers, Mental Capacity Act, Singapore, England & Wales, Renumeratoin



# Young Onset Dementia - Informal Carers perspectives on formal and professional support post diagnosis.

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

This was a small qualitative study of 6 informal carers of people living with YOD in Northern Ireland. Using statistics published in May (2023) it was estimated that 2000 people are living with Young Onset Dementia in Northern Ireland.

Main findings from the study were classified into five main themes.

Professional awareness of Young Onset Dementia and its management: Due to the younger age, general health is good and the person is dismissed as not being ill and there is a higher probability of symptoms of a rarer dementia.

Professionals not listening to informal carers before diagnosis: Informal carers identified that all was not well but were not heard due to GDPR and patient confidentiality.

Expectations of Social Care: Domiciliary Carers coming into the home are not specialised or trained in dementia care and raised the burden for informal carers.

Lack of Support around Systems: Social care and welfare systems are difficult to navigate and informal carers spoke of being left to 'get on with it'.

Support for Informal YOD Carer: Informal carers are looking more for support and services for those they cared for than for themselves

**Conclusion:** There is little understanding of YOD and how it presents. More awareness of YOD is required in clinical settings, social care and with the general public. In domiciliary care, more information and specialised training in dementia is required. Better signposting of social and welfare systems and age appropriate services for people affected by Young Onset Dementia would be beneficial.

#### **Keywords**

Young Onset Dementia, Informal Carers, Support.



# **I21-005**

# The experience and needs of informal carers of people living with dementia in rural Vietnam: a qualitative study.

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Introduction:** Carers of people living with dementia living in rural areas face numerous challenges due to the progressive features of the disease, limited resources, and inadequate community support. Research on how carers experience dementia caregiving in Vietnam and similar lower-middle-income countries in Asia is limited. This study aimed to explore the features and needs of caregiving among those carers in a rural district - Thach That - in Hanoi.

**Methods:** We recruited 20 participants (people with dementia and their carers) and employed a qualitative study design that involved using semi-structured interviews. Data were transcribed verbatim and analysed by applying phenomenological thematic analysis.

**Results:** The results revealed a total of 04 major themes about caregiving challenges and need: 1) Misconceptions about dementia 2) Duties and difficulties in caregiving (i.e., caregiver role, dependency for activities of daily living, behavioural and psychological symptoms, caregiving overload, communication challenges); 3) Coping and social support (i.e., inadequate coping strategies, lack of information, limited social support services); 4) Consequences and impacts on carers (i.e., role captivity, changes in day to day life, financial constraints, impact on physical and psychological health, feelings of embarrassment). The key areas identified by the carers as requiring support were dealing with memory loss, toileting and incontinence care, managing repetitive behaviour, and improving communication.

**Conclusion:** Thematic analyses revealed the challenges of caregiving related to behaviour disturbance, functional care needs, communication and financial challenges. Understanding carers' experience is essential in developing effective carer support services to reduce caregiver burden and improve the quality of care. Findings from the present study highlight the stressors of burden and unmet needs of carers of community-dwelling people with dementia, which may serve as a guide for future service development.

#### **Keywords**

dementia, caregiver burden, people living with dementia, thematic analysis, interview, qualitative study, Vietnam



# Satisfaction towards the Meeting Centre support programme: An empirical study with older adults living with cognitive impairment in Italy.

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Background:** The Meeting Centre represents an integrated low-threshold approach aimed at providing support both to the person living with dementia and carers to help them cope with the disease. Among group activities there are cognitive stimulation, reminiscence, and motor activities such as dance-movement activities by using the Hobart Method. Activities are chosen based on the individual capacities to benefit from them that are previously evaluated through a psychosocial assessment. Attention is paid to the environment and all those aspects which can promote a more enjoyable and beneficial experience. Activities are integrated and carried out sequentially based on participants' inputs.

**Aims:** The aim of the present study was to examine research participants' levels of satisfaction and perception towards the Meeting Centre support programme.

**Method:** The sample was composed of 66 older adults attending Meeting Centres in Rimini, which is a city in the Emilia-Romagna region of northern Italy. They were equally distributed among those diagnosed with Mild Cognitive Impairment (N=35), and those living with mild to moderate dementia (N=31). Most participants were female (n=40), and the average age in the sample was 79 years with a standard deviation of 6 years (range: 65-94 years). A participant satisfaction questionnaire was developed to reflect satisfaction with location, services and features, staff and activities, emotional aspects and general satisfaction. In addition, the questionnaire contained open-ended questions to collect users' point of view about overall experiences and perceptions.

**Results:** The results indicated that most participants rated their satisfaction highly across all domains. More than eighty percent stated they were very satisfied with staff, and report emotional relief related to sharing and feeling understood.

**Conclusions:** The Meeting Centre represents a support programme model allowing people living with dementia and carers to access friendly, community-based support which is designed around their individual needs and preferences.

### **Keywords**

Meeting Centre, Support, Dementia, Mild Cognitive Impairment



# Unpaid carers' experiences of supporting people with dementia to use social media

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## **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

**Aim:** Research suggests that social media can be a valuable resource for people with early-stage dementia. Yet, little is known about the perspectives of unpaid carers, who may have concerns about online engagement and unique experiences of actively supporting usage of social media. Due to this absence of previous research, we took an exploratory approach to understand unpaid carers' experiences of supporting people with dementia in their social media usage.

**Method:** Unpaid carers (n=234) of people with dementia responded to an online survey about attitudes towards people with dementia using social media and any experiences supporting this usage. Responses to closed questions were analysed using frequency analysis; qualitative data underwent reflexive thematic analysis.

**Results:** Fifty-five carers (23.5%) in the sample cared for someone with dementia who uses social media. These carers helped people with dementia navigate the complex interfaces of social media, providing ongoing technical support and guidance. Carers used social media to support care, by facilitating social connections and stimulation. However, carers also recognised the vulnerability of people with dementia on social media and took actions to uphold their dignity, safety and security. While carers generally saw the benefits of supporting social media usage, they also acknowledged it was labour-intensive and emotionally demanding. They carefully managed how people with dementia engaged with social media to create supportive and safe online experiences, striking a balance between the perceived benefits, online safety and security, and the demands of care.

**Conclusion:** Our findings shed light on the complexities of caring in the digital age. A substantial proportion of carers are supporting people with dementia in using social media. As social media usage continues to grow among an ageing population, carers, organisations, and policymakers must adapt to this digital landscape and work alongside technology developers to ensure safe and supportive online experiences.

### **Keywords**

digital inclusion, social networking, digital support, caring, online safety



# Inpatient Mental Health Care for People with Dementia.

**Dr Ben Underwood**<sup>1,2</sup>, Dr Emma Wolverson<sup>3,4</sup>, Mrs Naomi Thompson<sup>5</sup>, Dr Ming Hsu<sup>5</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

Mental health care wards (MHWs) (psychiatric wards) care for people living with dementia (PLWD) who are distressed and cannot be cared for in other settings. They are amongst the most complex and vulnerable people in the whole of healthcare. The quality of care provided within MHWs has not been the focus of any substantive rigorous research and remains a significant but unexamined site care for PLWD. This presentation will demonstrate the current research evidence on the care of people with dementia within mental health wards. We will highlight areas for more research and showcase a new innovative project designed to improve the care of people within mental health wards. We present the results of two systematic literature reviews and an analysis of 500 consecutive admissions to these wards. The first review sets the scene by establishing what is known internally about the characteristics, care and outcomes of people with dementia admitted to mental health wards and the data from 500 admissions in the UK. The second examines the evidence base for non-pharmacological interventions in this setting, including our recent data examining the impact of music therapy on two of these wards during the pandemic. Finally, we outline an innovative research study (MELODIC), funded by the National Institute for Health and Care Research, which will co-create a music therapy intervention to be delivered within wards as a way to reduce distress.

### **Keywords**

mental health ward, distress, BPSD, music



# **Doctor's Orders: Engagement to Deprescribe**

#### **Mr CHRIS COELHO**

Abe's Garden Community, NASHVILLE, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

### **Abstract**

This presentation will provide a pragmatic approach to reduce medications for older adults living with dementia in a senior living community. There is no lack of research, articles, and discussions on the importance of reducing polypharmacy for older adults, specifically those living with dementia. There are many repercussions and side effects that can arise due to polypharmacy including adverse drug reactions, falls, and increased confusion. This presentation will discuss how an interdisciplinary team in a real world setting can reduce the number of medications a person is taking.

For over two decades the Hearthstone Institute has been a leader in non-pharmacological interventions to increase the quality of life for older adults through the "I'm Still Here" approach. This approach along with a methodical system to deprescribe has decreased the use of medications over time for Abe's Garden Community residents. Instead of instantly using medications to address behaviors for older adults, engagement and a person directed approach are a way to supplement medication needs. No matter which stage of dementia a person is living in, this approach can have profound effects not only on reducing medications but on increasing a person's quality of life. Abe's Garden Community reduced the percentage of residents taking 9 or more medications by over 20% in a one-year period using an interdisciplinary approach.

This presentation will discuss how an interdisciplinary team uses strategies, management, and an outcome-based approach to improve a person's quality of life in a memory care setting.

# **Keywords**

Deprescribe, Dementia, Innovation, Senior Living



# Psychological work with delusions and hallucinations in dementia as an alternative to antipsychotic medication - an overview of methods illustrated with case studies

#### Mr Reinhard Guss

British Psychological Society, Leicester, United Kingdom. Oxleas NHS Foundation Trust, London, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

**Aims:** Auditory and visual hallucinations and delusions such as Capgras syndrome are frequently experienced in Lewy Body Dementia but also occur in Alzheimer's or Vascular Dementia. This presentation will give an overview of psychological, non-pharmacological approaches to working with hallucinations and delusions, illustrated by recent case examples.

**Method:** Cognitive rehabilitation strategies informed by Neuropsychology and brain injury rehabilitation are combined with person centred approaches in listening to and collaborating with people with a dementia diagnosis who experience hallucinations and delusions, and including their care partners.

Three in depth case studies are presented: auditory hallucinations, visual hallucinations and Capgras syndrome, looking at engagement, the experience of the person and their care partners, describing strategies used and showing some of the visual aids used during the treatment. There is an emphasis on the experience of the person with dementia and sharing their words and views.

**Results:** The case studies describe replacing the use of antipsychotic medication with psychological approaches and strategies, and the improvement of side effects of medication, reduction of distress and improvement of quality of life of the persons with dementia and their care partners.

**Conclusions:** Psychological approaches based on person centred neuropsychology and cognitive rehabilitation are shown to be effective in replacing antipsychotic medication and improve quality of life for people with dementia experiencing delusions and hallucinations.

### **Keywords**

Neuropsychology, collaboration, hallucinations, delusions, non-pharmacological approaches,



# Unveiling the Himalayan Treasure: An ethnopharmacological exploration of traditional healing practices of Sikkim's (India) Flora against Alzheimer's disease

**Dr Biswajit Bose**, Ms Reena Chhetri SRM University Sikkim, Gangtok, India

## **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

### **Abstract**

Sikkim is a small state endowed with rich traditional culture and floral biodiversity, situated in the lap of Eastern Himalayas. The tribal and rural population of Sikkim lives in remote rural areas, land locked by dense forest. Herbal medicine is the dominant system of medicine practiced by the various indigenous tribes in Sikkim Himalayan region for the treatment of various diseases, out of which few are utilized on commercial basis. Since it is difficult to afford modern medical treatment, local traditional healers use traditional systems using lives-saving aromatic and medicinal plants from nearby forests for the treatment of various diseases since ages. This present research involves the comprehensive examination of specific practice techniques, and remedies used against Alzheimer's disease within the regions cultural and traditional framework. It aims to provide in-depth insights into how these traditional healing practices are applied in real-life situations, offering a rich and Alzheimer's disease (AD) specific understanding. In depth interviews with traditional ethnic healers was carried out with open-ended and structured questionnaires, followed by detailed documentation on traditional medicines and medicinal plants. Further, in-depth bioactive metabolite profiling and ethnopharmacological characterization of the traditionally used ethnomedicinal plants were evaluated against key enzymes linked to Alzheimer's disease. Through the extensive interviews with seventy-six traditional healers, a total of seventy-five important medicinal plants from thirty-two plant families were documented with more than six hundred bioactive molecules, which were used to prepare various formulations to treat illnesses categorized under mental diseases. Galantamine and rivastigmine are two licensed anti-AD drugs based on plant-derived natural products. Therefore, by bridging traditional ethnomedicinal knowledge with modern scientific methods, the research can lead to the development of novel treatments or therapies for Alzheimer's disease, which may incorporate both traditional practices and pharmaceutical advancements

### **Keywords**

Alzheimer's disease (AD), Traditional healer, Ethnic communities, Ethnopharmacolocal characterization, Drug discovery, Sikkim Himalayas, India



Innovation in dementia care: Memory Lane Games: Al-enabled Personalised Digital Reminiscence Platform for Dementia with In-home Remote Monitoring, delivering structured cognitive stimulation for improved outcomes in socialisation and behaviour management with simple yet fun digital games. Our platform monitors and manages cognitive decline across neurological conditions, beginning with dementia.

#### **Mr Bruce Elliott**

Memory Lane Games Limited, Castletown, Isle of Man

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

Memory Lane Games stands at the forefront of dementia care innovation. Winners of the 2023 Mayo Clinic and ASU MedTech Accelerator in March and named semi-finalists in the £4.2M Longitude Prize for Dementia. We are improving the lives of people living with dementia - and their families and carers - with structured cognitive stimulation, frustration-free design and errorless learning combined with gamification and personalized digital reminiscence. We've crafted a platform where people living with dementia engage with games tailored to their evolving cognitive levels, offering an experience that seamlessly combines entertainment, reminiscence, and importantly, improves socialization.

Prioritizing co-design, we've partnered with ADI members including ADAP (Philippines) and UAA (Uganda), who've helped shape our engagement models which the Mayo Clinic and ASU Accelerator judges noted as "... useful and usable, simple yet scalable and able to impact millions of lives." Our platform is designed to dynamically adjust to each individual's needs, optimising engagement, triggering positive memories and socialisation. Our success is evident: over 100,000 app downloads, thousands of hours of gameplay every month, and games played in 134 countries.

Early indications from our 2023 RCT Clinical Trial Pilot include:

92% of carers felt the app made them more relaxed.

67% of carers felt the app made them happier.

66% of carers believed that time spent using the app worthwhile

58% of carers believed it had helped the person with dementia communicate more.

33% of carers reported the app had a positive impact on the person with dementia's thinking abilities

#### For moderate dementia:

92% of cases at least maintained severity of dementia over the 6 month study (17% of cases showed a decline in severity)

Our vision is to be a beacon of hope and innovation in dementia care for generations to come, all around the world.

### **Keywords**

Dementia, Memory Lane Games, Cognitive stimulation, Platform, Carers, Innovation, Socialisation, Reminiscence, Mayo Clinic, ASU MedTech Accelerator, Engagement



# Let's Have Fun: Activities to Engage People Living with Dementia

**Dr Marie-Eve Bolduc**, Mrs Claire Webster, Prof Nancy Forget

McGill University, Montreal, Canada

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

Engaging in meaningful activities can contribute to the physical, cognitive, and psychological wellbeing of people living with dementia (PLWD) and help them maintain a sense of personal identity. In addition, activities with a social component have been found to improve both activity engagement and care partner satisfaction. However, selecting activities that are appropriate and engaging for PLWD is often difficult given the unique skills and challenges of each person.

Students from the Master of Science (Applied) Occupational Therapy Program at McGill University have created an activity booklet specifically designed for PLWD and their care partners. The Dementia Activity Booklet was designed to bring care partners and PLWD together through activities that promote creativity and add to their quality of life. The booklet can be accessed free online in French and English. It contains more than 40 activities divided into six sections: creating and crafting, brain games, physical activities, activities that stimulate the senses, household activities and social events. Detailed instructions and safety tips are provided for each activity. Furthermore, ideas on how to adjust each activity based on the person's social, physical and cognitive abilities are provided. Care partners who have used the booklet reported that it positively impacted the quality and frequency of the activities they share with the PLWD and their satisfaction with them.

Working in collaboration with McGill University's Dementia Education Program, the booklet has now been enhanced and transformed into captivating videos that brings to life the activities featured within its pages, evoking a profound sense of connection and emotion. These videos not only offer valuable safety guidance but also cater to a diverse range of abilities. Thoughtfully crafted through a lens of empowerment, they unlock a world of possibilities and foster bonds through accessible and engaging activities.

# **Keywords**

activities, leisure, occupational therapy, well-being, quality of life, participation



# How Reimagining Dementia Can Help Us ALL Embrace Uncertainty, Learn to Listen, Lead with Our Hearts and Create a Better World

Ms Mary Fridley

East Side Institute, New York, NY, USA. Reimagining Dementia: A Creative Coalition for Justice, New York, NY, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

Across the globe, a growing movement of people living with and impacted by dementia is raising the question: How do we create radically humanistic alternatives to the shame- and stigma-laden "tragedy narrative" that keeps dementia surrounded by a dehumanizing "cone of silence" even though millions are touched by dementia across the world? And how do we create "communities of belonging" in which everyone – especially and including PLwD – is supported to grow and to lead? And how can we embrace dementia as an opportunity to break out of the often unimaginative ways we know how to see and be in the world?

People living with dementia, care partners, activists, academics and artists are developing and advocating for approaches to practice and policy that support everyone in the "dementia ensemble" to grow and to creatively express their humanity. We will present on one of these approaches and two projects it has informed: Reimagining Dementia: A Creative Coalition for Justice and The Joy of Dementia, both of which support us to:

- Create with, rather than control, difficult life situations
- Listen in ways that promote intimacy and discovery
- · Create environments that welcome our emotionality, shame, fears, conflicts and more
- Build a world (and systems of care) in which diagnosis is not the end of life but the starting point for but a starting point for joy, humanity, growth and new possibilities.

And to discover together how to have more connection, growth, inclusion, hope...and yes, joy in even the most difficult of life situations.

### **Keywords**

dementia, reimagine, joy, growth, play, performance, creativity, social change, tragedy narrative, social justice, community, collaboration



# Life isn't over after a diagnosis of dementia; I endeavour to live a purposeful life and having a purpose in life.

### **Mr Alister Robertson**

Dementia Alliance International, Bellaire, USA. Alzheimers New Zealand, Napier, New Zealand

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

Firstly, ageing is the leading risk for onset of Alzheimer's and other dementias. Secondly, most prominent role in the onset of Alzheimer's, is played by "family history and genetic risk factors". Can't do anything about it, too late to change your parents.

In absence of a cure or treatment risk reduction is most feasible. 40% of dementia cases could be preventable/delayed by addressing 12 risk factors.

Risk reduction does not end at diagnosis. Can progression be delayed by targeting our lifestyle choices such as exercise, diet and maintaining social connections?

This presentation will identify the choices I have made to try and slow the progression of my Alzheimer's.

Could I have done something earlier to prevent the onset of dementia? Who knows, no point looking back, my only focus is moving forward.

I am also doing my best to raise awareness, influence policy, make the world a better place for all of us who live with dementia.

New Zealand, dementia needs to be a health priority. Our Government needs to deliver robust risk reduction strategies as proposed in the Dementia Action Plan.

Build cognitive resilience/reserve. Notion that exercising and stretching the brain is an important way of keeping it healthy is widely accepted. If brain is exercised, it can retain and add reserve. What mental activities do I do and enjoy and likely to persevere with versus challenge of something new and does not appeal.

What have I tried (and avoid) regarding diet after learning that diets should be rich in fibre, exclude processed foods, include vegetables and fruit ,and avoid too much meat and fat. I will talk about the activities I do to relax to ensure my wellbeing.

Has dementia given me a new purpose in life?

### **Keywords**

diagnosis, purposeful life, life choices, risk reduction, cognitive reserve, cognitive resilience, mental activities, diet, progression, exercise, social connections



# Lessons learned from the creation of an international research collaboration on lifelong learning for people living with dementia

Dr Diana S. Thoft<sup>1</sup>, Dr Geir Berg<sup>2</sup>, Dr Alison Ward<sup>3</sup>

<sup>1</sup>University College of Northern Denmark, Aalborg, Denmark. <sup>2</sup>Inland Norway University of Applied Sciences, Hamar, Norway. <sup>3</sup>University of Northampton, Northampton, United Kingdom

### **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

### **Abstract**

Researchers from Denmark, Norway and the UK share their reflections and the lessons they have learned in establishing an international research collaboration to advance an evidence base for an innovative psychosocial intervention for people living with dementia in the community using a lifelong learning approach.

Each country is delivering the lifelong learning programme, which is underpinned by the ethos that people living with dementia can continue to learn and develop and so benefit from lifelong learning. The programme was inspired by cognitive stimulation therapy and neuro-pedagogy, which provides a holistic psychosocial and teacher-led programme of activity to support those living with dementia.

Researchers from the three countries have been collaborating for several years to plan, pilot and develop an evidence base to support this programme. The benefits of this international cross disciplinary working have led to shared knowledge, the development of innovative projects and ideas, alongside personal and professional growth. The challenges of funding, identifying commonly translated measures and exploring the nuances of cross-cultural delivery in each country will be reflected upon. The international research team will also share how they are overcoming these obstacles to deliver collaborative research. The future opportunities for this international collaboration will be discussed.

### **Keywords**

Research, collaboration, cross-disciplinary, lifelong learning



# Let's Get Engaged: Evidence-based Strategies for Creating Engaging Dementia Programs

Ms Sharon Johnson<sup>1</sup>, Ms Susannah Dwyer<sup>2</sup>

<sup>1</sup>Hearthstone Education Institute, Nashville, USA. <sup>2</sup>Abe's Garden Community, Nashville, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

Abe's Garden Community, located in Nashville TN, is a leading provider of residential and day programs for individuals living with dementia. Equally important, it is a site of research and training, serving as an incubator for the study and dissemination of best practices in architectural, interior, and landscape design; family engagement; direct care; programming; operations; and workforce development. The I'm Still Here® education was researched and developed through funding from the National Institutes of Health.

The I'm Still Here® approach is an innovative, evidence based, non-pharmacologic methodology for providing persons living with cognitive impairments with a high level of authentic engagement regardless of the severity of their dementia. The principles used in the training have consistently demonstrated that they can increase levels of meaningful engagement, participation, satisfaction, success and quality of life for persons living with memory challenges. Research studies have demonstrated that Hearthstone's I'm Still Here® approach has a statistically significant positive effect on the following areas: Quality of Life (6% increase), Depression (41% decrease), engagement (28% increase), and anxiety (42% decrease).

This session will offer attendees a theory-and-practice style presentation that combines the basic aspects of this state-of-the-art dementia methodology with their application in a real-world setting using examples drawn from their use at Abe's Garden and other Centers of Excellence, as well as provide participants with practical tips and solutions they can use to increase engagement for residents in their own memory care programs.

### **Keywords**

Innovation, Evidence Based, Non-Pharmacological, Dementia



# The Well-Being of People with Dementia in Sweden and Hungary from the Perspective of Relatives: A Qualitative Interview Study

Ms Jenny Nilsson<sup>1</sup>, Dr Ingrid From<sup>1</sup>, Dr Berit Gesar<sup>2</sup>, Ms Judit Staller<sup>3,4</sup>

<sup>1</sup>Dalarna University, Falun, Sweden. <sup>2</sup>Center for Clinical research, Dalarna Region, Falun, Sweden. <sup>3</sup>Dalarna University, Departmen of Health and Welfare, Falun, Sweden. <sup>4</sup>Semmelweis University, Budapest, Hungary

## **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

**Aim of the study:** to examine how relatives perceive the well-being of people with dementia who live in nursing homes and how nursing staff contribute to the well-being of the residents they care for.

**Method:** a qualitative study with a phenomenographic approach was applied. Semistructured interviews were conducted, five in Sweden and five in Hungary.

**Results:** the perceptions of well being of the relatives resulted in five categories of factors that could impact negatively or positively on a person's well-being: "Nursing care is adapted to the needs of the person with dementia", "Nursing is carried out by a sustainable care team", "The social needs of the person with dementia are met", "The person with dementia participates in meaningful activities", and "The person with dementia shows signs of feeling well".

**Conclusion:** From the perspective of the relatives, well-being can be created for people with dementia if nursing is person-centred. Professional development among staff and more time set aside to socialize with the person with dementia is needed to increase well-being. Well-being for the person with dementia can also be attained if the person with dementia gets to retain their social network and if staff has a supportive manager. Relatives are an essential cooperative partner in person-centred dementia care in nursing homes. The results of this study provide a basis for improvement in the care of people with dementia, which also may contribute to more cost-effective dementia care.

### **Keywords**

Dementia, person-centred care, phenomenography, relatives, well-being.



# Outdoor based support for people living with dementia

**Prof Anthea Innes**, Prof Vanina Dal Bello-Haas, Ms Equity Burke, Ms Mason McLeod, Mr Dylan Lu McMaster University, Hamilton, Canada

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

**Aim:** To report on outdoor based support and care for people living with dementia from the perspectives of people living with dementia, their care partners and older adults, and organizations providing outdoor based or recreation and social support to people living with dementia.

Methods: Data was collected in South West Ontario between January and June 2023.

We held 6 focus groups (n=37) with people living with dementia n =15, care partners n=9 and older adults n=13).

Two outdoor based walking focus groups [go-along interviews] were conducted with 17 PLWD/CP/OA participants.

We conducted 4 focus groups (n=17) and 1-1 interviews (n=12) with staff from organizations providing outdoor, recreation or social programming.

All interviews and focus groups, other than the walking focus groups where field notes were used, were audio-recorded and fully transcribed verbatim. A thematic analysis, within and across each participant group dataset, was conducted following Miles et al.'s (2014) phases of: i data condensing, ii. data display iii. drawing conclusions.

**Results:** We will consider the four common themes across both participant groups: Challenges of achieving full participation in outdoor based activities; Perceived physical, social and mental health benefits of outdoor activities; Stigma/concerns about disclosing a dementia diagnosis and; Overcoming perceived risks.

**Conclusion:** This study demonstrates the importance of the outdoors for people living with dementia and their care partners. It aligns with the World Health Organization focus on dementia as a public health priority requiring creative approaches to provide high quality support and care. It has implications for care policy and practice relating to the promotion of (social) health and wellbeing for people living with dementia.

### **Keywords**

Outdoor based care; wellbeing; people living with dementia; care partners





# A creative arts approach to working with people living with younger onset dementia and their families to support interpersonal engagement and enhance personhood.

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### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

**Introduction:** People living with younger onset dementia often look for services that fit their unique needs, with a focus on family relationships, socialisation and maintaining selfhood. This case study research explored the use of a Neuro Dramatic Play (NDP) approach, delivered as an innovative creative attachment-based arts, drama and play approach to support younger people with dementia and their caregiver(s), providing valuable insight into the potential benefits of such engagement, and identifies ways in which this approach could be up-scaled to support others living with younger onset dementia through everyday activities.

**Method:** Two 10-weekly workshops were run with people living with younger onset dementia. Engaging with 13 individuals, of which three attended as couples (two married couples and one as siblings). The workshops were developed using NDP as the theoretical underpinning for the work. Research was conducted alongside the delivery of the session through pre, post and 8-month post-measures of quality of life, attachment and resilience. These were supported by interviews at the same time points and a review of workshop videos.

**Results:** The project found that this approach can support an individual's creativity and imagination. Through the workshops, participants developed their sense of identity; found a safe space away from outside pressures; a chance not to focus on dementia; supported memory through embodied movement, found ways to communicate through creativity, with each other and enhanced facets of external relationships.

**Conclusions:** The approach and use of creativity can support people living with younger onset dementia and their caregivers.

### **Keywords**

Drama, Younger Onset Dementia, Family Support, Personhood, Creativity, Arts



# Re<sup>2</sup>ignite: An interdisciplinary Psychosocial Innovation for Persons living with dementia

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### **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

**Introduction:** Established in 1994, Ren Ci Hospital is a voluntary welfare organization in Singapore. Given the long trajectory of dementia, support rendered must be adaptable and finely attuned to the evolving needs of persons living with dementia (PLWD). Re2ignite is a multidomain intervention program tailored to meet the biopsychosocial and spiritual needs of PLWD and their care partners. With the *Spark of Life* Philosophy as a guiding principle, Re2ignite adopts a social prescription approach to match PWLD to suitable sub-programs tailored to meet the unique needs and challenges at early, mid, late stages of dementia and bereavement for care partners. This presentation seeks to compare the well-being of PLWD before and after a multidisciplinary intervention program.

**Methods:** A prerequisite assessment is conducted by trained *Spark of Life* Club facilitators to determine each participant's Club level. The programs within Re2ignite are then recommended for participants based on their Club level – advanced-stage specialized rehabilitative care, moderate-stage art therapy, and early-stage cognitive support. For Care Partners, social and psychoeducational sessions were organized alongside bedside and Mass memorials sessions to honor and remember those who have passed.

The Bradford Well-being Profile (WBP) was used to measure changes in well-being for before, during, and after the session. Each program runs for 10 weeks with an outing for Care Partners where qualitative feedbacks were obtained.

**Results:** Preliminary findings suggest that there has been an average increase of 10.7% in the WBP of the participants, and 98% Care Partner satisfaction from evaluation questionnaires.

**Conclusion:** This case study demonstrated the benefits gained from a multidisciplinary program in relation to the well-being of PLWD. Multi-sensory elements enrich the experience whilst allowing engagement at various stages of dementia. Its formal outcomes have illustrated the Re2ignite's project success. Early intervention of non-pharmacological approaches with PLWD adds value towards care.

## **Keywords**

Dementia research and innovation, Non-pharmacological intervention





# THE "SOUND" STUDY PROTOCOL: A NON-PHARMACOLOGICAL MUSIC-BASED INTERVENTION FOR OLDER PEOPLE WITH DEMENTIA AND DEMENTIA CARE PROFESSIONALS

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# **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

**AIMS:** The SOUND project, funded by the Erasmus+ programme (contract 2021-1-IT02-KA220-ADU-000033494) is aimed at designing an original music-based curriculum for dementia care professionals and testing a pilot music-based non-pharmacological intervention with older people with dementia and care professionals in Italy, Portugal and Romania. The SOUND method offers an innovative blended intervention based on music activities and cognitive stimulation approaches made in circle, which was co-designed by musicians, health professionals, older people with dementia, family caregivers and researchers, for its application in dementia settings. The purpose of the paper is to describe the detailed procedure of the quasi-experimental pilot study.

**Methods:** The pilot study will be the first implementation of the SOUND intervention to investigate its feasibility and preliminary. The experimental phase uses a mixed-method design encompassing qualitative and quantitative observations, cognitive testing, self-report and interviewer-assisted questionnaires to investigate the effectiveness of the intervention for 45 people with dementia and 45 professionals (15 in every study country: Italy, Portugal, Romania). The pilot study will be carried out in Autumn 2023.

**Results:** Among the expected results are a decrease in dementia care professionals' work-related stress and burnout, an improvement in older people's mood and wellbeing as well as the maintenance of cognitive capabilities.

**Conclusions:** The novelty of SOUND is its multicomponent method including the most evidenced features for improving the wellbeing of participants. The study can help bring scientific evidence of the positive effect of music on people with dementia so that such non-pharmacological interventions become common in formal and informal care settings.

### **Keywords**

care professionals, dementia, music-based activities, non-pharmacological intervention, older people, protocol



# Combined multimodal exercise and cognitive training for older adults with mild dementia: A mixed-methods four-arm pilot randomized controlled trial

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## **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

#### **Abstract**

**Aims:** Studies are lacking to examine 'the more the better' phenomenon among persons with mild dementia (PwMD) by combining exercise and cognitive interventions. This study aimed to evaluate the feasibility and preliminary effects of a caregiver assisted combined multimodal exercise and cognitive training (CA-MECT) intervention comparing with exercise or cognitive training alone and attention placebo control group in PwMD.

**Methods:** This study adopted a mixed-methods design comprising a pilot four-arm randomized controlled trial and a qualitative study. Participants in the combined interventions group received a 12-week CA-MECT: a three-phase caregiver assisted multimodal exercise and cognitive training (70 min/session, 3 sessions/week), delivered via Tencent Meeting, supplemented with home-based training. The multimodal exercise or cognitive training group received caregiver assisted multimodal exercise (CA-ME) or caregiver assisted cognitive training (CA-CT), while the control group received health education. A battery of validated instruments was used to evaluate global and domain cognitions, neuropsychiatric symptoms (NPS), instrumental activities of daily living, and health-related quality of life.

**Results:** CA-MECT was feasible regarding recruitment and intervention implementation, with no reported adverse events. Qualitative interviews showed the CA-MECT was highly acceptable to the dyads. Participants in the CA-MECT group significantly improved global cognition ( $\beta$  = 3.89, 95% CI [1.98, 5.81], p < 0.001), immediate recall ( $\beta$  = 5.11, 95% CI [1.63, 8.58], p < 0.001), the number ( $\beta$  = -1.98  $\square$ 95% CI [-3.27, -0.69], p < 0.05) and the severity of NPS ( $\beta$  = -3.50, 95% CI [-5.61, -1.40], p < 0.05), and caregiver distress ( $\beta$  = -3.25,95% CI [-5.44, -1.06], p < 0.001) compared with control group but comparable with exercise and cognitive training alone.

**Conclusion:** CA-MECT is feasible and effective in improving cognition and NPS among PwMD.

### **Keywords**

Combined interventions, multimodal exercise, cognitive training, dementia, randomized controlled trial



# An integrated concept of peri- and postdiagnostic support in Austria

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

Postdiagnostic support not only strengthens self-determination and enables participation, but also offers additional benefits for people with dementia, their families and carers. In Austria, the comprehensive approach of peri/postdiagnostic support falls under the seven goals of the Austrian dementia strategy "Living well with dementia" and is therefore considered important for integration into the health sector.

Currently, there are several peri/postdiagnostic support projects in Austria in the different provinces, as a systematic survey from 2022 shows. In order to ensure current and future decision-making for affected persons and relatives, special interventions and structures are necessary in the different federal provinces. Therefore, a concept is currently being developed that outlines the framework conditions, regulations, interventions as well as specific indicators and categories for a qualified and constructive implementation. In addition, the diverse care, counselling and support services as well as the self-help groups can be coordinated and interlinked.

The concept should help to efficiently integrate the comprehensive approach in the different regions and ultimately incorporate it into the long-term care system. The first results, indicators and activities are presented.

### **Keywords**

integrated care, postdiagnostic support, peridiagnostic support



# Assessing the efficacy of an integral art-based cognitive intervention for older adults with Alzheimer's disease

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## **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

**Background:** The emergence of COVID-19 highlights the need for large efforts to develop new technologies and other interventions to improve the prevention, treatment, and management of Alzheimer's disease (AD). Thus, we developed an integral art-based cognitive intervention (IACI) program using a method of combining online intervention and offline intervention, to evaluate the biological effects of IACI in mild AD patients, primarily the cognitive and psychological health gains.

**Methods:** This is a prospective, randomized wait-list controlled trial with allocation concealment and blinding of outcome assessors and data analysts.44 participants were recruited from memory clinic, assigned to intervention group (n=22) and wait-list control group (n=22), received the 60-90 minutes, 16-week, 24-session IACI program (11online, 13 offline). Global cognitive function, specific domains of cognition (memory, language, executive function, attention, and visuospatial skills), and other health-related outcomes (quality of life, anxiety, depression, loneliness, sleep quality, and physical activity level) were measured at baseline, immediately after the intervention, and at the 6-month follow-up, and a linear mixed model was applied.

**Results:** Of the 44 participants, 38 and 31 completed the questionnaires immediately after intervention and at follow-up, respectively. Post-intervention, the intervention group showed significantly greater improvement than the control group in general cognitive functions, specific domains of cognitive function (language, memory, and executive function), anxiety, depression, sleep quality, and sense of loneliness. Follow-up, significant group differences remained only in general cognitive functions, and specific domains of cognitive function in memory.

**Conclusions:** These findings suggest that the IACI program may be an effective non-pharmacological intervention option for older adults with mild AD and that continued participation may be beneficial in AD prevention and care. For the withdrawal rate of participants during the follow-up period increased owing to the COVID-19 pandemic, the results should be interpreted cautiously.

### **Keywords**

Alzheimer's disease, art therapy, cognitive function, randomize controlled trial, psychological health





# **Some Dance to Remember - Celtic Connections**

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## **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

Some Dance to Remember – Celtic Connections is a collaborative research project involving All Irish Dance and the Technological University of the Shannon in Limerick, Ireland, and Alzheimer Scotland in Dundee, Scotland. The project compares the effects of participation by people living with dementia and their dance partners in pilot community dance projects in Limerick, Ireland and Dundee, Scotland. Medical students from the University of Dundee on placement with Alzheimer Scotland undertook four weekly sessions of adaptive Scotlish country dancing, with parallel sessions in Limerick Ireland using adaptive Irish céllí dance as their core activity, for people living with dementia and their carers. Separate focus groups along with reflective discussions among the dance facilitators in Ireland and Scotland yielded several similar themes, including:

- Adaptive dance as a Connection to Irish/Scottish Culture.
- Social Interaction and Support.
- Communication/Information Sharing within Dementia Care systems.
- Caring Roles and community activities as mini-respite opportunities.

This presentation will provide insight into the development and implementation of the "Some Dance to Remember" pilots in Ireland and Scotland, while exploring the potential benefits of culturally relevant adaptive social dance in the community as a social and practical support for all who engage with it.

### **Keywords**

Dementia, dance, movement, adaptive dance, social dance, community, connection, support networks, inclusion, Ireland, Scotland



# Language use in multi-infarct/vascular dementia as seen in 238 YouTube posts

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### **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

**AIMS:** Until vascular dementia, specifically VDmi, combines with another dementia, especially Alzheimer's Disease, it is hard to diagnose or to suggest non-pharmacological interventions that sponsor socialization. Our aim is to study language change over time in a corpus of VDmi language.

**Methods:** We trace language change as well as technological outreach throughout five years and 238 YouTube postings by one man. He composed these postings to let others know what living with vascular dementia is like and to increase his own opportunities for socialization.

**Results:** We draw on findings by Macoir (2023), who summarizes analyses in VDmi and on studies of dual brain hypotheses by Van Lancker Sidtis and Sidtis (2018) and especially on familiar/formulaic language by Sidtis (2021) and Wray (2012).

**Conclusion:** The corpus of VDmi video posts shows the impact of current technological contexts (instructed or self-taught) on retention and reuse of language produced by persons living with dementia as well as having value for outreach and intervention development for others with similar conditions.

Key References:

Macoir J. 2023. Language impairment in Vascular Dementia. Journal of Geriatric Psychiatry and Neurology0(0) 1–9. DOI: 10.1177/08919887231195225

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### **Keywords**

vascular dementia, online interactions, corpus analysis





# What is intended by the term "participation" and what does it mean to people living with dementia?

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## **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

Policy continues to emphasise the importance of wellbeing in dementia. However, there is a vital need for psychosocial interventions that can promote positive outcomes to enhance "living well with dementia". Our developing understanding of what people living with dementia report as being important to them, has resulted in new interpretations of what constitutes wellbeing including constructs such as "growth", "purpose" and "participation". These exciting and important constructs are not currently captured by outcome measures within dementia research. This limits our understanding of the value of psychosocial interventions. This paper explores the concept of participation and how continued participation in social life can make a difference to the rights of people living with dementia as citizens. We will firstly consider why participation is important for how we might measure outcomes in dementia research and care. Secondly, we will explore how we might measure participation. Finally, we will consider the value of participation as a psychosocial outcome in future research.

# **Keywords**

dementia, participation, outcome measurement, citizenship, human rights



# The challenges in keeping post-diagnosis community-based support groups for people living with dementia going, long term: Learning from the Get Real with Meeting Centres project

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

**Aims:** Supporting people with dementia to live well at home in their communities, post-diagnosis, is a global goal. However, in the UK third sector/community-led initiatives often have to fill gaps in community-based support offered by health and social care systems, yet face a challenging landscape and struggle to sustain support long term. Get Real with Meeting Centres was a two-year investigation into the long-term sustainability of Meeting Centres (MCs), a still-developing form of community-led support for people with mild to moderate dementia.

**Method:** A Realist Evaluation incorporated interviews/group discussions with MC attendees, carepartners, staff, volunteers, trustees and professionals/practitioners supporting them at three case study sites in England and Wales; and with people offered/offering places at 13 MCs in one case study region regarding barriers to attendance. A national survey regarding what people value about MCs was also conducted.

**Results:** 98 people took part in interviews/group discussions, from which 94 causal 'context-mechanism-outcome' statements were produced on: Referrals and care pathway issues; Reaching people and membership; Carer engagement and benefit; Venue and location issues; External relationships and collaboration; Internal relationships and practices; Finances and funding. 122 survey responses highlighted a strong preference for people to stay with their current MC offer, valuing a broad mix of types of activity, with opportunities to use/learn skills.

**Conclusions:** Concluded to help sustainability were: A clear, joined-up care pathway making appropriate referrals, with appropriate provision to follow MCs; Emphasising social inclusion at MCs; A wide range of activities tailored to preferences/needs; Engaging family carers; Access to transport/drop-off facilities; A stable, appropriate venue; Supportive partnerships between community groups (local and regional); Collaboration over competition; Adherence to the ethos and purpose of MCs; Careful financial management; Longer-term funding opportunities supporting social inclusion and stable post-diagnostic support beyond acute medical needs.

### **Keywords**

community-based; group support; post-diagnosis; psychosocial; third sector; peer support



# "It's almost as though dementia is a hot potato – no-one wants to hold it and handle it": How dementia stigma influences access to community and emergency care

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

**Aim:** Emergency department attendance among people with dementia can be distressing and risks complications. Although there is evidence to suggest a link between accessing community services and using the emergency department, the link is not well understood. Therefore, we aimed to explore the experiences of accessing community and emergency care among people with dementia and current and bereaved caregivers.

**Method:** Semi-structured interviews were conducted online and over the telephone with people with dementia and current and bereaved caregivers who had been purposively sampled. Interviews explored experiences of living with dementia and accessing community and emergency care, and views of the emergency department. Interview transcripts were analysed using reflexive thematic analysis.

**Results:** We conducted 35 interviews with 37 participants (people living with dementia=10, current caregivers=11, bereaved caregivers=16). Three themes were reported: 1) Navigating a 'push' system, 2) Emergency department as the 'last resort' and 3) Taking dementia 'seriously'. Altogether, the themes suggest that people affected by dementia encounter multiple barriers to access care in the community and use the emergency department as the path of least resistance. These barriers were due to an overstretched system that fails to prioritise people affected by dementia, reflecting wider societal stigma.

**Conclusions:** Our analyses suggest that there is urgent need for dementia to be better prioritised and seen on a par with other life-limiting conditions. This includes provision of long-term dementia care to improve access to care in the community and caregiver support as health navigators, and safely reduce the use of the emergency department.

## **Keywords**

Community care, emergency department, healthcare access, dementia stigma, post-diagnostic care, qualitative interviews



# Meeting Centre Support Programme in Singapore: An Update on Findings and Learning Points

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

Following findings that multicomponent support programmes are more effective than single support activities or psychosocial interventions for persons with dementia and their families, and evidence that earlier intervention for such persons smooths their adaptation to dementia, the Meeting Centre Support Programme (MCSP), a multicomponent support programme model developed first in the Netherlands and the United Kingdom, has been piloted in Singapore from July 2020.

Dementia Singapore has been actively reaching out to other community partners to start Meeting Centres. Training and support are provided to the community partners to guide the implementation of MCSP. There are now six Meeting Centres in Singapore supporting 56 families. Families are either self-referred or referred through formal and informal networks, including Post Diagnostic Support Services, Community Outreach Teams, and grassroots organisations.

Based on the evaluation done for the two pilot centres for the initial three years, caregivers have shown to have either maintained or increased gains in dementia caregiving across six-monthly assessments, as measured by the Gain in Alzheimer care Instrument (GAIN) score; mixed results were observed for caregiver burden and loneliness, and the quality of life of persons with dementia has also shown mixed results. Nevertheless, the drop-out rate for Meeting Centres has remained low, and attendance, high, while persons with dementia demonstrate elevated mood and engagement during sessions.

The past three years' experience have highlighted learning points: (1) Meeting Centres should collaborate with local community care services such as the Community Outreach Teams (CREST) and Community Intervention Teams (COMIT) to address the varied needs of persons with dementia and caregivers; (2) as members progress beyond mild dementia, care should be taken to transit members to the services appropriate for their developing needs, and members can continue to receive support during such care transitions.

### **Keywords**

Meeting Centre Support Programme, MCSP, Post-diagnostic support, PDS, Psychosocial interventions, Persons with dementia, Adjusting to Change, Caregiver gains



# The lived experiences of people using dementia services.

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

**Aim.** The broad aim of this research is to understand the lived experiences of persons living with dementia (PLWD) and their care partners from diagnosis through accessing services designed to help them.

Method. In collaboration with a hospice that has recently launched a dementia course, and after obtaining University ethical approval, we collected narratives from 5 PLWD and 28 care partners. We asked people to tell their own stories using a journey concept. We manually analysed the data using thematic analysis.

Results. We uncovered journeys beset by delays, access barriers, power struggles, and fear. Table 1 provides illustrative quotes. Early journey stages were characterized by significant

	Table 1: Verbatim Quotes Illustrating Key Themes
	Initial Journey Stage: Diagnosis
Delays in diagnos	is
Reluctance	"By now it was November. I mean this had taken a year plus, we're going into our second year" (Francis, 70, care partner to husband)
Denial	"It's not so easy for me, taking phone calls and talking about Jim and Jim's condition when Jim's there. I just can't do that to him because I'm just reminding him that there's a problem because quite a lot of the time, he's not aware of it, and I think that's a nice way to be for both of us. I wear hearing aids, so I have to put the phone on speaker phone" (Catherine, 18, care partner to husband).
Power	"So [we] went to the doctor's and I think that's where I kind of did find a frustration. Because nobody really wanted to know They all said, "Well he's
imbalance	fine, you know, there's not a problem at all." And there is me back at home thinking, I know it's a problem!" (Gayle, 66, care partner to husband).
COVID-19	"But then you know we were getting towards the end of 2019 and of course we then got Covid. So, we were then essentially just left. And things did progress and get worse. I found that really, really difficultAnd nobody really seemed to want to know at that stage" (Harry, 77, care partner to wife).
	Journey Stage 2: Seeking Access
Gaps in support p	ost-diagnosis
Feeling alone	"I remember him (doctor) telling me I'd got to learn to behove like a saint. You know, we all have-He didn't say, "Well, it's going to be tough," etc, "you've just got to behave like a saint". That wasn't very helpful, no. Not very impressed with the service from the [memory] clinic. It seemed to be a case of go on this medication, go away, and live with it" (Keith, 82, care partner to wife).
Problems with follow up	"So we're getting around to 12 months since initial diagnosis kind of thing, or whatever. And it was then that I rang Social Services. I said, "You sent a fellow around 11 months ago. What came out of that?" "Oh, oh, oh yes, there is a report." Well, I never saw itSo whose benefit was that for?" (Rachel, 53, Caregiver to her father)
Information avai	ability
Imprecise diagnosis	"There are 200 different types of dementia. I don't know which one it was, or even if it was or what. So, it doesn't really help" (Jane, 76, PLWD).
Information overload	"The thing that I felt was the fact that everybody was really keen to provide you with information. I was overwhelmed with information. But nobody did anything practical" (Barbara, 84, care partner to husband).
Digital literacy	"I think it would be better if somebody would come out and speak to you. Because I can't use a computer. So, I can't do the internet or anything like that. So, I find it difficult to contact people" (Rose, 87, care partner to husband).
Referral	
Serendipity	"Next door, but one, my neighbours, she worked with dementia. And her husband still does. So, in desperation, because I just didn't know which way to turn, I went to them. They're very goodVery nice neighbours. And she gave me a list of charities that I could ring" (Madeline, 68, care partner to husband).
Word-of-mouth	"My daughter, who is a pharmacy technician, she works at the doctor's surgeryand she had a word with the ladies there and they sent me a book, they sent me piles of leaflets all about it and they got me in touch with a club which we go to every other Tuesday" (Dawn, 70, care partner to husband).

delays due to reluctance to admit a problem. A power imbalance between medical professionals and care partners caused further delays, as did the pandemic. Post-diagnosis, we identified gaps in support and problems caused by service complexity. Information provision is problematic, and referral to appropriate services tends to be serendipitous. Actual service experiences, once access is navigated, is well-received, though coordination between services remains problematic, and there are major gaps in service provision.

**Conclusions.** Providers of dementia services need to work more closely with their service users to better understand their lived experiences. Information provision needs to be reconsidered, and providers need to understand that not all service users are digitally literate. Finally, providers need to understand their place in a wider network, and more needs to be done to foster collaboration and communication between providers.

### **Keywords**

Dementia services, lived experiences, hospice



# Unmet care needs for Community based people living with dementia and their caregivers in Lusaka-Zambia.

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

#### AIMS:

To assess the prevalence of unmet care needs of community based PWD and their informal caregivers in Lusaka.

Determine the baseline demographics of PWD and their informal caregivers

Identify the independent predictors of unmet needs among PWD and their informal caregivers

**Methodolgy:** This was a cross sectional study which included 33 community based people living with dementia each with a caregiver. The participants underwent a one-time in-depth in-home assessment which enabled collection of information including socio-demographic characteristics, clinical characteristics including dementia severity using the Mini mental State exam, measurement of performance in activities of daily living and impact of supporting someone with dementia. Assessment of care needs was based on the John Hopkins Dementia Care Needs Assessment tool. Bivariate and multivariate regression analyses were conducted to identify demographic, clinical, functional and quality of life correlates of unmet needs as well as identify the independent predictors of unmet needs among PWD and their informal caregivers

**Results:** The mean proportion of unmet needs for patients with dementia was 57% while that of caregivers was 62%. Significantly higher unmet needs were associated with having attained a tertiary education and having an unknown type of dementia. Patients living with dementia had higher unmet needs in the domains of meaningful activities, legal issues and advance care planning and resource referral while caregivers had higher unmet needs in the domains of community resources, respite and mental health counseling.

**Conclusion:** The study identified that patients with dementia and their informal caregivers had a high prevalence of unmet care needs in multiple domains. It also demonstrated that in this particular cohort, having a tertiary education and an unknown type of dementia was significantly associated with a higher proportion of unmet needs.

### **Keywords**

unmet needs, informal caregiver, respite, resources



# No-one left to cope alone (NOLA): Progress made on the development of a post-diagnostic intervention to support people adjusting to a dementia diagnosis.

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# **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

**Background:** Receiving a diagnosis of dementia can have an extreme emotional and psychological impact on the person being diagnosed and on their families. However, despite this, there is a lack of provision of post-diagnostic support for people to process the impact of this diagnosis in United Kingdom National Health Service (NHS) services.

**Method:** Over three phases of work, the evidence base for a new post-diagnostic intervention to support people processing a dementia diagnosis and their families will be developed. In Phase 1, two systematic reviews will be conducted to identify post-diagnostic interventions for psychological adjustment to a diagnosis of a mental or physical health condition and to identify successful psychosocial interventions for people living with dementia. In Phase 2, a qualitative research study will be undertaken to further understand the impact of a diagnosis of dementia and to identify key components that should form part of the new intervention. Alongside Phases 1 and 2, an Advisory Board of people with dementia and carers will contextualise findings using their own experience and produce key recommendations for the new post-diagnostic intervention.

**Results:** Work commenced in August 2023, with updates on progress to be presented at the conference. Both systematic reviews have been registered on PROSPERO and data analysis on identified studies is ongoing. Preliminary results from the qualitative research study will also be available.

**Discussion:** The NOLA project seeks to develop a new intervention for people who are adjusting to the psychological and emotional impact of receiving a diagnosis of dementia. Using evidence from literature and qualitative research with people with dementia, we will develop an evidence based and feasible intervention that has been co-developed with our advisory board.

### **Keywords**

post-diagnostic support, psychological adjustment, emotional impat.



# Demencja Jesteśmy Razem" ("Dementia We Are Together")

- Bringing people living with dementia, care partners and the community together to inspire purpose, meaning and hope

Mrs Marlena Meyer<sup>1</sup>, Dr Urszula Skrobas<sup>2,3</sup>, Ms Magda Kaczmarska<sup>3</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

### **Abstract**

The sentiment "Nothing About Us Without Us" has been adopted by people living with dementia and care partners around the globe resulting in advances in care, representation and policy. However, the systems that ensure this inclusion are not universal. People living with dementia and care partners in Poland face similar conditions as many in other regions of the world, where despite a growing incidence of dementia, healthcare systems do not provide effective support after receiving a diagnosis of dementia. The result leaves people living with dementia and their care partners with a sense that "nothing can be done". The lack of a National Dementia Plan and of universal systems of support further a sense of isolation and despair. Inspired by leading advocacy groups in Australia, the UK and the United States, the community, "Demencja Jesteśmy Razem" are working with people living with dementia, care partners and the organizations that serve them to drive change and inspire hope. This online community meets bi-monthly on Zoom and continues conversation on WhatsApp to provide education, offer support, champion advocacy efforts and connect resources. Education topics range from neuroanatomy to participatory arts and non-pharmacological interventions. Moreover, members support one another. The group is multi-generational and includes many people living with young onset dementia, highlighting a need for more awareness, early diagnosis and support to extend the quality of life of these individuals. Several initiatives have grown out of this work, including a research project into clinical manifestations of young onset dementia in Poland, access to clinical research studies among members, and the formation of the Polish Working Group of People Living with Dementia and Care Partners. This presentation will feature reflections from members of the group on the gaps in service in Poland and a vision for the future they hope to see.

### **Keywords**

dementia care, people living with dementia, carers, person-centered approaches, inclusivity, advocacy, awareness, education, post diagnostic support



Presenting the Amelesia Training Programme. A Communicative Approach. Learn to hold sustained conversations with people living with dementia. Piloted in 2018 by 16-18 year-old students in England, this programme teaches current understanding of dementia with face-to-face workshops and visits to residents living in a care home.

Dr Mina Drever

MinaDrever Limited, Great Easton, Essex, United Kingdom

# **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

The WHO's 2017 exhortation that educational programmes be developed 'to encourage dementia-friendly attitudes ... targeting different groups ... including students and teachers' (Global Action Plan), coincided with the conception of the Amelesia programme, the result of linguistic analysis of conversations held with my mother who lived with dementia.

Underpinned by theories of communicative language learning – prompts, cues, questions that lead to appropriate responses, listening – students learned to hold sustained conversations with residents in a care home. All participant students said that everybody should do this programme. Here are two students' comments (sic):

I thought it was very helpful to learn how to talk with residents with dementia, especially as the disease is becoming more prevalent in society.

It makes you aware of the different challenges dementia brings and teaches you how .... to understand the resident as a person.... to communicate with a person with dementia without being derogatory or insensitive while giving them control over the conversation.

The students' teacher witnessed students' development in 'greater understanding of the challenges facing elderly people ... their empathy and communication skills'.

The care home manager said that the students' visits 'made a visible difference to the residents' lives ... it has emphasised the importance of the feel-good moment enhancing residents' well-being'.

The Amelesia programme fulfils the ADI's call that 'education must be improved and expanded ... starting early in schools ... (to) break stigma and encourage deeper understanding' (World Alzheimer's Report 2022).

A repeat of the pilot is planned for 2023-2024.

### **Keywords**

dementia, brain diseases, Alzheimer's, education, conversations, training programmes, visiting, stigma, attitudes, learning



Mixed-heritage families surviving dementia: cross-cultural perspectives. (This paper records contemporary histories of migrant families in managing degenerative diseases affecting human cognition and human memory. An anthology of testimonies are provided by family carers of mixed heritage ancestries who are challenged by conflicting norms, ideas and expectations of managing Dementia.)

Mrs Diane May Allen WEST

University of the West Indies, Mona, Kingston, Jamaica

### **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

### **Abstract**

This study focuses on families of mixed-heritage coming into awareness of dementia, adapting to realities of living with a family member diagnosed with dementia and finally, coping with dementia and its effects in a foreign space or where at least one carer or affected person is an immigrant. A crosscultural perspective attempts original research on how diversity shapes 'living with dementia' experiences since the families selected are mixed with both Afro-Caribbean and European ancestries and wherein their coping mechanisms are adopted from clashing, often conflicting, cultural dispositions such as: contrasting indigenous perspectives and social obligations towards ageing family members, feelings of cultural displacement and differing expectations of support from the wider national healthcare infrastructure. These cases are indicative of how cultural-hybridity nuance health-crisis management and how converging variables such as first and third-world norms affect collaborative decisions for the care of persons with dementia. Significant findings of the study are that outcomes are almost always based on family-location factors. That is, questions of where culturally or ethnically mixed families are living at the time and how they are able to access resources or overcome communication barriers, contribute directly to quality of care. The case studies also reveal significant first/third-world cultural clashes on issues of 'trust' in the family management of dementia particularly where conflicts arise between the reliance on synthetic pharmaceutical medicinal treatment versus the belief in natural herbal nutritional cures as decelerators to cognitive degeneration. There are also trust-subjectivities whereby human-interaction is preferred to technological-aid-stimulation and wherein for all cases, there is almost zero awareness of how artificial intelligence might be of practical use. The study derived primarily from families living in the UK, Netherlands, Jamaica and the United States, provide useful anecdotal evidence for conducting transcultural studies in public health management and further research in socio-medical histories.

### **Keywords**

mixed-heritage, cultural-hybridity, cultural-displacement



# Singapore's Second National Survey of Attitudes Towards Dementia

### **Prof Rosie Ching**

Singapore Management University, Singapore, Singapore

## **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

Post-COVID-19, Singapore's second nation-wide survey on dementia since the first in 2019, gained 3226 respondents in five weeks, across population demographics of age, race and gender, quantifying the national landscape relating to persons with dementia, their primary or secondary caregivers and the general public with no connections to dementia. Serving Dementia Singapore, Singapore Management University statistics faculty Rosie Ching crafted the extensive survey exceeding 230 variables and together with her 71 statistics students, actively conducted the survey at dementia daycare centres, door-to-door at apartment blocks, malls, shops, hawker centres, train stations and with families, relatives and friends, probing into knowledge levels, beliefs, attitudes, awareness of support available and their efficacy. In the subsequent statistical analysis of perceptions, 6 in 10 say they are treated as less competent than usual, with one in two feeling incompetent and embarrassed about their condition, citing stigma as the main reason. More than 75 per cent think Singapore is markedly less than dementia-friendly and that stigma around dementia is as prevalent as it was in 2019, with more than half of people with dementia still rating their inclusion level in everyday life at less than 30%. This is even as the rejection, loneliness and shame they face have dropped significantly from 72 per cent to 31 per cent across these four years.

The findings reinforce the presence of significant prevailing stigma associated with dementia, especially with Singapore the oldest society in ASEAN, and predicted by the UN to have the world's oldest population by 2100.

### **Keywords**

Singapore, dementia, national, covid, survey, caregivers, students, education, stigma, perceptions, attitudes, competence, embarrassment, shame, rejection, efficacy, knowledge, action



KòMee - (Come Along) connects people with younger onset dementia and young adults, studying human science in higher education. Students take persons with younger-onset, out of the group in residential /day care centers, doing individual, meaningful activities or duo volunteer work, according to wishes and needs. We also offer Communication Methodology.

Mrs Elena de Ru<sup>1,2</sup>, Mr Paul Braem<sup>3,4</sup>

<sup>1</sup>KoMee vzw, Ghent, Belgium. <sup>2</sup>Trainer - Education TPR, national and international, Netherlands. <sup>3</sup>Director residential/ ay care center, Bruges, Belgium. <sup>4</sup>KoMee vzw, West - Flanders, Belgium

# **Topic**

**Dementia awareness:** Diverse populations – inclusion, equality, cultural issues

#### **Abstract**

KòMee (foundation) Come Along, connects people living with younger onset dementia and young adults, studying human sciences in higher education.

We offer the opportunity of doing individual and meaningful activities with people with younger-onset, staying in residential- or day care centers, outside the traditional internship structures but within the curriculum of their education. The activities take place both inside and outside the organization with mutual respect, as much equality as possible and, above all, according to the needs and wishes of the person in the target group.

During their time with KòMee, we offer the students additional training in Communication Methodologies, in collaboration with museums from the cultural heritage sector at the initiative of KòMee partner: museum 'Huis van Alijn' (Ghent), which has further adapted the 'Object Handling' methodology in close collaboration with a KòMee coordinator. Culture and heritage are used to create natural equality between students and people with younger onset.

We recently added an extra approach: A person with younger-onset may form a duo with a student, to participate in regular volunteer work. If necessary and useful the student takes on a protective role. The person with younger onset can remain active in society and in his environment in an optimal manner, adjusted to own wishes, possibilities and/or interests.

Started in 2018 with 11 students from 1 faculty and 11 participants from 1 location, we currently yearly reach over 120 people with younger onset, in various cities and many more students from 7 different institutions of higher education.

The participants highly enjoy and look forward to KoMee students

Students grow in self confidence and benefit within their own families (grandparents with later onset) and in future carriers.

Care Centers enjoy the nice, individual approach we promote.

Colleges and Universities like to work with KoMee! (led by volunteers)

### **Keywords**

Intergenerational, inclusion, university students, younger onset, communication methodologies, natural equality between students and people with younger onset, volunteers. changing attitudes



# EQUAlity of opportunity for TimEly dementia diagnosis (EQUATED); a qualitative study exploring the lived experiences of prodromal dementia in minoritized ethnic communities in East London, UK.

**Ms Christine Carter**<sup>1</sup>, Prof Claudia Cooper<sup>1</sup>, Dr Moise Roche<sup>1</sup>, Dr Sarah Morgan-Trimmer<sup>2</sup>, Prof Yvonne Birks<sup>3</sup>, Dr Mark Wilberforce<sup>3</sup>, Prof Charles Marshall<sup>1</sup>, Prof Kate Walters<sup>1</sup>

<sup>1</sup>Queen Mary University, London, United Kingdom. <sup>2</sup>Exeter University, Exeter, United Kingdom. <sup>3</sup>York University, York, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Importance of cultural context training for carers/provider

#### **Abstract**

In our qualitative study, we examined the lived experience of prodromal dementia in minoritized ethnic residents of East London. We investigated how individuals from diverse Background:s perceive the changes preceding a dementia diagnosis, how symptoms present, their understanding of these symptoms and whether they lead to consultation and diagnosis.

Timely diagnosis empowers people to understand their symptoms, make plans and access appropriate treatments. People living in less affluent areas and from minoritized ethnic groups often receive dementia diagnosis later, and the diagnostic process is characterised by inaccuracies. This inequality arises from various factors including misattribution of symptoms to normal ageing, stigma, and insufficient professional knowledge about appropriate diagnostic tools.

To ensure diversity, we aimed to recruit 40-60 individuals aged (60+) in East London using a purposive sampling frame. Our participants included 10 individuals living with dementia, 27 family members, (including 2 paid carers), who were predominantly from Bangladeshi and African Caribbean communities, and 21 professionals involved in diagnosing dementia or supporting those with symptoms. All participants provided informed consent.

We conducted in-depth semi-structured interviews between April-September 2023 using remote video-calls or face-to-face meetings. We developed a topic guide and coding framework with input from Patient and Public Involvement (PPI) collaborators and the clinical and academic team, iteratively generating four themes.

Help Seeking; exploring responses to symptoms and the triggers that prompt families to seek help.

Labelling and trust, examining stigma, beliefs and language surrounding dementia symptoms, which can complicate diagnosis

Immigrant experiences, highlighting the desire for movement when dementia symptoms arise among first-generation immigrants.

Cultural challenges, addressing language barriers and the importance of cultural sensitivity in making experiences understood.

Our study suggests a need to adapt UK dementia diagnostic pathways to accommodate different help-seeking priorities and styles, emphasizing cultural competence through, awareness, engagement and collaboration.

# **Keywords**

Equality, Minoritized ethnic communities, Access to dementia diagnosis, Prodromal dementia symptoms, East London, Deprivation, Multi-cultural, cultural competence, diversity, Lived experiences,



# Perceptions of the term chi dai zheng (痴呆症) – different views amongst the participants

Mrs Mei Champ<sup>1</sup>, Dr Jennifer NW Lim<sup>2</sup>, Prof Richard Cheston<sup>1</sup>

<sup>1</sup>University of the West of England, Bristol, United Kingdom. <sup>2</sup>University of Wolverhampton, Wolverhampton, United Kingdom

### **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

**Aim:** The aim of this study is to understand how strongly Chinese individuals feel about the term chi dai zheng (痴呆症) for dementia and whether this term hinders their willingness to seek early diagnosis.

**Methods:** This research deploys an online quantitative questionnaire and promoted through Chinese centres in the UK and via Facebook. The questionnaire consists of 35 questions through online Dementia Attitudes Monitor. One of the questions was to ask the participants to identify their preferred terms from a list of options. These options were chi dai zheng (海呆症), shi zhi zheng (失智症), tui zhi zheng (退智症), nao tui hua zheng (脑退化症), other, or all acceptable. This paper examines the respondents' preferred choice(s) of terms for dementia.

**Results:** All 107 participants were Chinese, mostly resident in the UK. The results were that 39% chose chi dai zheng (痴呆症), 17% shi zhi zheng (失智症), 26% tui zhi zheng (退智症), 52% nao tui hua zheng (脑退化症), 11% other term, whilst 33% considered all terms to be acceptable. Interestingly, 6.3% participants chose both chi dai zheng (痴呆症) and nao tui hua zheng (脑退化症) as their preferred terms.

**Conclusions:** The results from the questionnaire are not definitive. A significant proportion of participants (39%) chose chi dai zheng (痴呆症) although a greater number (52%) preferred nao tui hua zheng (脑退化症), while 33% thought that all terms are acceptable. Further studies need to be carried out to gain a deeper understanding and the impact of the medical term chi dai zheng (痴呆症) for dementia.

### **Keywords**

dementia, dementia attitudes, chi dai zheng (痴呆症), brain health





# DECIDE - Diverse experiences of End of Life Care for dementia - Establishing Consensus and Capacity for future research through Collaboration and Co-production

**Dr Marie Poole**<sup>1</sup>, Dr Louise Tomkow<sup>2</sup>, Ms Margaret Ogden<sup>1</sup>, Mr Malcolm Ngouala<sup>1</sup>, Dr Faith Tissa<sup>1</sup>, Ms Maria Karagiannidou<sup>3</sup>, Dr Efioanwan Damisa<sup>2</sup>, Ms Josie Dixon<sup>3</sup>, Prof Barbara Hanratty<sup>1</sup>, Prof Martin Knapp<sup>3</sup>, Dr Felicity Dewhurst<sup>1</sup>

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### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

### Abstract

**Background:** and aims: Dementia is a leading cause of death internationally. Yet end-of-life care is often poor or non-existent. People with dementia from ethnic minority or socioeconomically deprived communities are even less likely to receive good palliative care. Despite this, research into end-of-life care often fails to include people from these populations.

Our aim is to find out what research is required to improve end of life care for everyone with dementia and how inclusivity can be facilitated.

**Methods:** A scoping review of the academic literature (Medline, CINAHL, EMBASE, Psychinfo and Scopus databases) published between Jan 2000 to April 2023 was conducted, supplemented by citation tracking, reference checking and grey literature review. The health inequalities present for those with dementia at the end-of-life, how care barriers and facilitators differ across different ethnic, religious, cultural and socioeconomic groups and the current research gaps were shared with diverse key stakeholders through a series of workshops. Conclusions were then used to provide evidence-based recommendations for inclusive end-of-life care and future research.

**Results:** Themes form the literature played out in the personal and professional experience of key stakeholders. Society in general lacks adequate knowledge on palliative and end-of-life care and dementia, particularly as a terminal diagnosis. Palliative care providers lack awareness of the needs of those dying in the margins. There is a dearth of support services and a lack of appreciation of appropriate models of inclusive care for those with dementia and their families. Lack of funding perpetuates poverty and a lack of trust of those who commission and provide care.

**Conclusions:** Future research should focus on international education strategies, how optimal end-of-life care differs for those with dementia compared to other life-limiting conditions and appropriate models of inclusive, appropriately funded care.

### **Keywords**

End of life care, dementia, underserved populations, co-production



"The course gives me confidence to think critically and challenge practices I see that are not evidence based": Postgraduate dementia students' translation of education into practice

**Dr Emma Lea**, Dr Kathleen Doherty, Mrs Helga Merl, Dr Matthew Kirkcaldie Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, Australia

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Aims:** It is important to explore workforce participation in education aiming to enhance dementia knowledge, and the impact of such education on their understanding and agency to change systems and practices, to better support people who live with dementia. Few dementia-focused university courses exist, meaning that the impact of this type of course is under-studied. This study aims to investigate why people undertake postgraduate studies in dementia, and the impact of the course on their practice.

**Method:** This ongoing study is surveying students undertaking an online postgraduate course on dementia policy, prevention, care and support, and underlying neurobiology at an Australian university. Findings from 19 participants in the first recruitment round of August 2023 are presented, grouped by thematic analysis of responses to open-ended questions on how knowledge gained is used to influence practice.

**Results:** Participants were predominantly women, typically studying the Master of Dementia course while working in residential or community aged care or acute care. All agreed they were studying the course "to influence change". Participants reported that they frequently used knowledge from the course to influence their practice, particularly to educate or inform others and to change aspects of their own practice. Key themes from qualitative data on how the course influences practice were: using an evidence base to support practice; having the confidence to educate others (e.g., colleagues); and building skills to better support people living with dementia (e.g., communication strategies). Participants stressed the need for workplaces and professional organisations to recognise student learning.

**Conclusion:** Postgraduate education can play an important role in translation of knowledge about dementia into practice, which is critical in the context of the need to increase the knowledge, capacity, and resilience of those who support people with dementia and for development of the wider dementia policy arena.

### **Keywords**

Dementia education, postgraduate, workforce, survey





## Using VR to present 'real-life' scenarios to healthcare students: An evaluation study

Ms Rebecca Dew, Dr Michele Board

Bournemouth University, Bournemouth, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

Dementia education is vital for healthcare professionals and carers. With over 55 million people living with dementia worldwide, estimated to rise to 139 million by 2050 (WHO, 2022), there remain worldwide concerns around awareness of how to care for those with dementia and their symptoms.

New technologies including virtual reality (VR) simulations are being increasingly used in training healthcare professionals. However, both simulations of clinical settings and also male viewpoints are underrepresented in current scenarios within the literature on dementia. Using a mixed-methods approach, this study has developed a 360-degree VR simulation of a clinical setting, informed by conversations with people diagnosed with dementia and their carers. The study will use a pre- and post-design using the Confidence in Dementia Scale (CODES), as well as a focus group approach, to evaluate the VR video as an educational tool for healthcare students and potential implications for viewers' healthcare practice following a period placement.

Descriptive analysis will evaluate the CODES results and thematic analysis (Braun and Clarke, 2006) will be used to analyse the focus group(s). Data will be collected in September/October 2023 and a full report of the analysis and conclusions will be made available thereafter.

### **Keywords**

dementia, dementia education, virtual reality, simulation, VR, 360-degree video



## **Cultivation of Staffs on Dementia Care for 6 Years in A Day Care Center**

Ms Ying Hui Wu<sup>1</sup>, Ms Chia Yu Chiu<sup>2</sup>, Ms Hsiu Ling Lin<sup>2</sup>

<sup>1</sup>Twin-cheng Care and Create Studio, Taipei, Taiwan. <sup>2</sup>Sisters of Providence, New Taipei City, Taiwan

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### Abstract

**Background:** Sisters of Providence had registered in Taiwan in 1956. It had started community care services in 2001 in New Taipei County. A dementia and disability mixed type day care center was set up in 2010.

**Cases and Staff Education:** Up to August 2023, 56 attendants in the Center, among them 37 are the people with dementia. Professional full-time caregivers are 8, part-time 7. Besides, there are 2 social workers, 1 nurse, 1 deputy director and 1 director. Education for those staffs include further academy study, professional workshops in house, and regular training.

**Regular Training:** The training has been carried on quarterly from 2018-2023. The applications cover questionnaire, case discussion, reading, scenario practice, images, introduction of global and local care examples, music and arts, assignments etc.

**Crisis and Risks:** Due to the COVID-19 epidemic between 2020 and 2022, the Center was closed once for two and half months according to infection control crises which resulted in training restrictions. During the three years of strict regulations, there were special sessions for colleagues to talk about their plight in caring and provided international practices. In addition, based on the cases of the 2022 ADI's International Conference, the risk management of Ukraine and Indonesia during wars and earthquakes was introduced.

**Conclusion:** We will share training focuses, philosophy and approaches with flexible and practical methods to educate formal caregiver becoming a better professional oneself.

### **Keywords**

staff education, regular training, crisis and risks, flexible and practical methods.





### "I think the rose-tinted glasses do just sort of slowly come off": the development of empathy towards people with dementia in healthcare students

Ms Yvonne Feeney<sup>1</sup>, **Dr Stephanie Daley**<sup>1</sup>, Dr Nicolas Farina<sup>2</sup>, Prof Sube Banerjee<sup>2</sup>

<sup>1</sup>Brighton and Sussex Medical School, Brighton, United Kingdom. <sup>2</sup>University of Plymouth, Plymouth, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Aims:** To deliver effective person-centred care to people with dementia, healthcare professionals need to have the capacity and skills to practice with empathy. Greater empathy can lead to better patient relationships, reduced burnout, and enhanced recognition of personhood. However, people with dementia frequently report episodes of care that lack empathy. To improve the quality of care, effective dementia education needs to be provided at undergraduate level. To inform the design of suitable educational resources, this study aimed to understand the major factors that impact the development of empathy towards people with dementia during undergraduate education.

**Methods:** A longitudinal grounded theory study (Charmaz, 2014) was conducted. Semi-structured interviews took place in 2019 with undergraduate nursing, physiotherapy, and medical students (n=30). A second interview was completed with students (n=26) eighteen months later. Emergent findings were informed by simultaneous data collection and analysis using constant comparison techniques, and the use of theoretical memo writing.

**Results:** Findings suggested that the development of empathy towards people with dementia was impacted by social and emotional exposure during undergraduate years. Data centered on four subcategories. While there were barriers connecting and understanding people with dementia, students experienced conflicting expectations about empathy more widely. Positive and negative cultural experiences during placement led to emotional changes and a shift in ideals.

**Conclusion:** Environments that promote empathetic practice during clinical placement could impact the development of empathy in undergraduate healthcare education more widely. This study highlights a need for educational design that focuses on both the patient and the environment.

### **Keywords**

empathy, dementia, undergraduate education



## Dementia Care Accreditation Scheme to increase standards of care home dementia care practice.

### Mr Sam Dondi-Smith

Canterbury Christ Church University, Canterbury, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### Abstract

Occupational Therapist Sam Dondi-Smith has lead a team of experts to create an Accreditation Scheme for UK care homes which focuses on lifting standards of dementia care delivered by care teams in residential and nursing homes.

The scheme is delivered via an audit, measure, review and recommend process and is seeing positive results in the reduction of psychological and social challenges associated with late stage dementia. The areas of interest are based on the Dementia Care Innovation Framework (Dondi-Smith 2023) which breaks down the care of the person into three areas; the Environment, Team processes and personcentred approaches.

The scheme has so far been delivered to Lukestone Care Centre, Maidstone and Parkview Care Centre, Ashford and feedback has been positive from staff, residents and families who have seen an increase in qualitative wellbeing of residents and subjective competence of care staff in managing behaviours which present as challenging to them.

Care providers have also reported that they have benefited from expert input by Occupational Therapists and specialist psychiatric nurses with regards to recommendations on how they can improve their environment and team practice development.

It is now planned to roll out the Accreditation Scheme across the UK as results have been positive.

### **Keywords**

care home, accreditation, advanced, consultancy



# Supporting dementia support workers to adapt to their role within a primary care setting: what works, for whom and in what circumstances

**Dr Hannah Wheat**<sup>1</sup>, Ms Hannah Shafi<sup>2</sup>, Dr Tomasina M Oh<sup>1</sup>, Dr Lauren Weston<sup>1</sup>, Dr Sarah Morgan-Trimmer<sup>3</sup>, Dr Basharat Hussain<sup>1</sup>, Dr Paul Clarkson<sup>2</sup>, Prof Richard Byng<sup>1</sup>, Dr Michael Clark<sup>4</sup>

<sup>1</sup>University of Plymouth, Plymouth, United Kingdom. <sup>2</sup>University of Manchester, Manchester, United Kingdom. <sup>3</sup>University of Exeter, Exeter, United Kingdom. <sup>4</sup>LSE, London, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

Case management, within primary care, is increasingly viewed (and evidenced) as the most impactful approach to post-diagnostic support for people living with dementia.

Throughout the UK, dementia support workers (DSWs) have, to varying degrees, been given the role of case manager. While outcomes from DSW support are increasingly explored, little attention has been given to how best support DSWs to deliver personalised care. This is surprising as by attending to DSW support needs, their delivery of support can be enhanced and workforce retention could be improved. To better understand DSW support needs, insights into what contextual factors (e.g. previous experience, work-placed culture, availability of community resources) can affect their adoption and adaption to the role in various settings are required. Such insights can be used to ensure that initial and ongoing opportunities for development and support are based on what needs arise in practice. The Dementia PersonAlised Care Team (D-PACT) study has used a realist approach to develop and (currently) evaluate a primary care based DSW role. A core focus within D-PACT programme theory on how various forms of support (e.g. supervision, peer support, support from general practice surgeries), in certain contexts, can help trigger the type of changes in DSWs (e.g. increased knowledge of how to navigate the system) that can generate positive changes in DSW behaviour and longer-term outcomes. Within the study, a range of longitudinal qualitative data (e.g. interviews, observations, reflection logs) has been collected from 8 DSWs and those who have provided support. The analysis will test, elaborate and refine programme theory statements relating to when, how and for whom various forms of DSW support worked. This presentation will share the results of this analysis and provide evidence-based guidance on how DSWs can be best supported to deliver personalised care in practice.

### **Keywords**

dementia support workers, primary care, support, personalised care, realist analysis



## Video Technology-based Social Engagement Intervention for Caregivers of Persons with Dementia

**Dr Raksha Anand Mudar**, Ms Elizabeth Lydon, Dr Wendy A Rogers, Dr Minakshi Raj University of Illinois Urbana-Champaign, Champaign, USA

### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

Family caregivers of persons with dementia, many of whom are 60 years or older, assist their family members with multiple activities including activities of daily living and instrumental activities of daily living. As the demands of caregiving increase, caregivers' social circles shrink and opportunities for meaningful social engagement become limited leading to social isolation, loneliness, and negative health outcomes. The associated burden of caregiving has been typically addressed through in-person and web-based educational interventions and support groups. However, fewer interventions have leveraged technology to deliver easily accessible social engagement opportunities unrelated to the caregiving role itself. Thus, the goal of our CareEngage pragmatic pilot clinical trial is to evaluate the benefits of a video technology-based social engagement intervention on social, cognitive, and emotional health and quality of life outcomes in older caregivers. The CareEngage trial uses a staggered entry wait-list controlled design where participants serve as their own baseline. After participants complete a comprehensive baseline assessment, they enter a 4-week wait-list period. At end of the wait-list period, they complete another baseline assessment, followed by an orientation and entry into the intervention. As part of the intervention, participants are asked to attend 2 social engagement sessions per week for 4 weeks. During each session, they join others over Zoom for a casual 30-minute conversation on a topic (e.g., cooking, gardening, birdwatching). At the end of the 4-week intervention period, participants complete a postintervention assessment. This pilot trial is currently ongoing. The last wave of participants is currently enrolled and will complete the study in December 2023. A total of 78 caregivers (Age: 68.4 ± 6.6; Sex: 68 F) of persons with dementia have enrolled in the study. Intervention outcomes will be assessed once the final wave of participants has completed their intervention and results will be presented at the conference.

### **Keywords**

Family caregivers; social engagement; social isolation; loneliness; intervention; pragmatic trial; technology-based



## Helping Carers to Care: feasibility of the 10/66 Dementia Research Group caregiver intervention in rural Benin.

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### **Topic**

Support for dementia carers: Education and training for informal carers

### **Abstract**

**Aims:** In sub-Saharan Africa, the number of people living with dementia is expected to double every 20 years, from 2.7 to 7.6 million. Family members of older people living with dementia (PWD) often provide informal care but lack of knowledge and understanding about dementia leads to difficulties. The objective of this study was to determine the feasibility of the Helping Carers to Care (HC2C) caregiver intervention in rural Benin.

**Method:** This was a quasi-experimental (before/after) study conducted in 2022 in Djidja-Abomey-Agbangnizoun, Benin (West Africa). Two groups of 30 dyad (caregiver / PWD) were to receive the intervention in the beginning of the trial or six months later. The intervention consisted of three modules: 1) assessment (cognition); 2) basic education about dementia; 3) training regarding specific problem behaviours. Main outcome measures were assessed at baseline, at 3-month and at 6-month. For caregivers: strain (Zarit Burden Interview), psychological distress (SRQ-20), and quality of life (WHOQOL-BREF). For PWD: behavioural and psychological symptoms (NPI-Q) and quality of life (DEMQOL). Median scores and InterQuartile Ranges were calculated and compared between control and intervention groups at different study times.

**Results:** Due to difficulties in identifying dementia cases in the community, the study population consisted of 22 PWD and their primary caregiver divided into two groups - control and intervention - of 11 dyads. Both groups were similar with regards to sex, education, marital status, occupation, dementia severity but people in the control group were older. After intervention, only scores in participants' Quality of Life were statistically different in the intervention group, not carer burden or quality of life scores.

**Conclusion:** Preliminary results show that implementation is challenging in rural Benin, where dementia awareness is low and care structures are lacking, adding to the scarce evidence on feasibility and benefits of caregiver interventions in LMICs.

### **Keywords**

Caregiver, Intervention, Quality of life, Dementia, Strain, Feasibility, sub-Saharan Africa.



# The perspective of residents living with dementia towards the built environment in nursing homes – insights into a walking interview study

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### **Topic**

Dementia awareness: Dementia and design

### **Abstract**

**Aims:** In long-term care for people living with dementia, the built environment is recognized as a crucial aspect. The suitability of the built environment can be systematically assessed using assessment tools. For Germany, the German Environmental Audit Tool (G-EAT) was adapted. The process revealed that the perspective of people living with dementia was not sufficiently considered in the tools' adaptation. To explore their perspective, we investigated how residents living with dementia experience the built environment in nursing homes.

**Method:** Walking interviews with residents were conducted and audio-recorded. Inclusion criteria for participation were the presence of dementia (medically diagnosed or present by symptoms) and the ability to express themselves verbally in German. For data analysis, audio material was transcribed and augmented by the researchers' field notes and photographs. Interpretative-phenomenological data analysis was carried out using Braun & Clarke's reflexive thematic analysis to enhance comprehensibility.

**Results:** 14 residents from two nursing homes participated in the walking interviews without (n=9) or with (n=5) walking aids such as walkers or wheelchairs. Three main themes were identified: (1) Being able to maintain the feeling "to refurnish" or having to let it go, (2) experiencing the limits and potentials of being independent because of the built environment, and (3) living in a community of residents. This themes can be summarized in the essence: "The built environment can serve as a facilitator or barrier to residents' self-determination in the setting of a nursing home".

**Conclusions:** Findings indicate that residents do not see only their care unit as living space, but the whole nursing home. This broadens the perspective of existing structural definitions in the setting. Involving residents in the design and creation of this living space can help them to identify with the built environment and thus increase their sense of self-determination in everyday life.

### **Keywords**

dementia, long-term care, nursing home, environmental design, perspective taking, walking interviews, qualitative research, phenomenology



## Taking Insights from Non-dementia Friendly Homes to Facilitate Ageing In Place Design

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### **Topic**

**Dementia awareness:** Environment and architecture for dementia

### **Abstract**

Even if their perception of time and space has changed, a person with dementia lives in a world where relationships, objects and situations matter. Carers often encounter ageing individuals saying "I want to go home", even when they are already in their own home. The orthodox principles applied to the design of homes to accommodate the needs of ageing individuals are not really making sense in an ageing society. Misconceptions, such as persons living with dementia should be contained in specific environments and continuously under surveillance remain to be the focus of design approaches. Therefore, it is imperative that we understand the challenges a person with changes in cognition faces while ageing in their own home. The intention is to give direction to designing homes that can function until a person ages, which should unquestionably be compulsory to any home architecture. With the burden of healthcare costs, families may not have the means to modify their homes and sudden changes in dwelling can disrupt the environment of a home. Descriptive data were gathered from a survey disseminated to random Filipino families living with Dementia in private homes that are not dementia-friendly. In the Philippines, the choice of care is influenced by family culture and lack of specialised assisted facilities. Characteristics of a home environment that is favourable and unfavourable to a person with dementia were used to define the following architectural design considerations: Function and Comfort; Spatial Layout; Visual Access; Sightline; Accessible Space Dimensions; and Passive Design.

### **Keywords**

Dementia-friendly, Ageing in Place, Elderly-friendly Home, Designing for Dementia



### Alzheimer's shared houses, an alternative to the dual choice between home and nursing home.

### **Mrs Christine Tabuenca**

Fondation Médéric Alzheimer, Paris, France

### **Topic**

**Dementia awareness:** Environment and architecture for dementia

### **Abstract**

As a starting point, shared housing philosophy consists in "doing with" rather than "doing for" roommates.

When cognitive problems become too serious for people to remain at home, the only solution is often to move them to a nursing home. However, Alzheimer's "shared accommodation" is attracting increasing attention from all those involved in neurocognitive disorders. Aware of this challenge, Fondation Médéric Alzheimer conducted an ethnographic study describing 6 shared houses for people with dementia. The aim was to identify their benefits and obstacles to their development.

The most striking lesson is that setting up shared house within a dynamic partnership ecosystem is an essential ingredient for success. All partners are important, especially those outside health and medical-social fields (local authorities, shopkeepers, neighbours, etc.).

Moreover, families are also expected to make a regular contribution to the daily activities. As part of a community, they take part in the day-to-day running and management of the home and create a bond between themselves and the housemates.

Organising the medical care for which families are responsible is a sensitive issue in shared accommodation facilities.

Alzheimer's shared houses are innovative and complex to manage. As a result, project sponsors are discovering the expertise and skills they need.

They also highlight two professions that need to be (re)defined: "coordinator/facilitator", whose missions have yet to be defined, and homecare assistants, who can lack specific training in Alzheimer's condition but to whom working in shared house significantly improve their working conditions.

This type of accommodation facility is an alternative to a NH or home-based care. However, there is still one major obstacle: the high cost, which makes it an inaccessible solution for people on low incomes.

To establish an overview and recommendations, Foundation will launch in 2024 a quantitative survey of all the Alzheimer's shared houses.

### **Keywords**

shared housing, nursing home, family caregivers, home-based care





### Spatial inequalities in dementia care: A scoping review

**Dr Flávia Borges Machado**<sup>1</sup>, Prof Miguel Padeiro<sup>1,2</sup>, Prof Clarissa Giebel<sup>3,4</sup>, Prof Oscar Ribeiro<sup>5,6</sup>, Prof Liliana Sousa<sup>5,6</sup>, Prof Helena Nogueira<sup>1,2</sup>, Prof Paula Santana<sup>1,2</sup>

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### **Topic**

**Dementia awareness:** Environment and architecture for dementia

### **Abstract**

**Background:** The dementia journey for both people with dementia and care partners is subject to multiple pressures, which depend on local and individual characteristics, spatially differentiated characteristics, the allocation of resources, and the conditions under which ageing occur. Inequalities play out spatially and require a geographical lens to fully uncover the combined impacts. Despite growing evidence on several factors, such impacts have not been fully recognised until now.

**Objective:** This scoping reviews aims to map the way spatial inequalities have been connected to dementia care.

**Methods:** Six databases (Scopus, PubMed, Web of Science, Science Direct, PsyINFO and EBSCO Academic Search Complete) were systematically searched throughout September 2023. This review is restricted to peer-reviewed quantitative, qualitative or mixed-methods studies focused on: (i) people living with dementia as target population; (ii) spatial inequalities in access to resources and opportunities (services and support), and inequalities in exposure to supportive environments (e.g., physical, built, and social environments); (iii) published in English after 2007. A total of 7,687 records were identified. A narrative synthesis and analysis guided by the PRISMA-ScR is conducted.

**Results:** The preliminary results show a relevant number of studies addressing the impact of built environment or neighbourhood on the risk to develop dementia. But, after diagnosis, only a smaller number of studies addressed the impact of physical environment (e.g., objective characteristics of the physical context), social environment (e.g., quality of relations, socio-economic profile) or service environment (e.g., neighborhood resources and opportunities) in the dementia progression or symptomatology.

**Conclusions:** The body of literature needs expansion into how spatial inequalities affect people living with different subtypes of dementia and care partners, particularly in terms of access to treatment and social support. This review findings may provide some insights that can benefit policymakers in the planning of dementia-friendly communities.

### **Keywords**

dementia-friendly environments, major neurocognitive disorder, physical environment, social environment.



### People with dementia evaluating the built environment as coresearchers: Insights from a participatory action research project (INCLUDE)

Dr Saskia Kuliga<sup>1,2</sup>, Dr Jim Mann<sup>3,4</sup>, Prof Martina Roes<sup>1,2</sup>

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### **Topic**

**Dementia awareness:** Environment and architecture for dementia

### **Abstract**

**Aims:** INCLUDE originally was designed to include people with dementia in research about wayfinding and the built environment. The project's aim was to implement a participatory action research group to explore how the built and social environment facilitate navigational confidence during outdoor wayfinding in urban environments.

**Methods:** Methods included situated wayfinding evaluations, cultural probe methods, facilitated group discussions, and design thinking methods. We had not yet established a participatory action research group at the start of the project, and learned that people with dementia preferred to meet individually with the researcher. INCLUDE explicitly allowed a high flexibility in its methodological portfolio: people with dementia decided which research methods they wanted to engage in, and could set an individual research focus within the project's larger research topic.

**Results:** Preliminary results (e.g., about wayfinding or the built environment) focused on the individual coresearcher: their biography, preferences, habits and personality, to name but a few. Few co-researchers used the cultural probe methods, and the situated wayfinding evaluations occurred in inside or outside environments that were quite different in their characteristics. However, in true participatory action research practice, the project naturally shaped itself. In being open to what was possible and preferred by each individual co-researcher, both as method and research focus, we found the strength of the project: focusing on the individual co-researcher's lived experiences.

**Conclusions:** INCLUDE encountered various practical challenges that initially appeared to slow down the research but in fact shaped the project into a new direction. While generalization may be limited, the project offers unique insights to what role wayfinding and navigational confidence play for the individual. Conducting participatory action research projects can foster self-efficacy and may offer insights to individual experiences that may not yet be presented in the wayfinding research literature.

### **Keywords**

built environment, wayfinding, participatory action research (PAR), design thinking, inclusive design



## Mapping access to outdoors in the experience of the dementia care environment – a cross-cultural study.

### **Dr Alexia Mercieca**

University of Malta, Msida, Malta

### **Topic**

Dementia awareness: Dementia and design

### **Abstract**

The data presented here is a portion of a larger PhD study that explored the impact of dementia care environments across different continents, with an interest on the perceived daily life experiences of people with dementia in their dementia care environments and their immediate outdoor settings.

The study is focused on the value of the sense of self through the dementia journey, and the extent to which this is supported within a given care environment. In doing so, it proposes a critical assessment of traditional care settings that are generally characterized by clinical, enclosed environments, with little to no relation to the outdoors, and are heavily reliant on the safety and security of the residents, through themes of spatial legibility, cultural appropriateness, fascination, user-centredness and personalization. The novelty of the study lies in the approach of the environmental assessment, which is phenomenological in drawing on the individual experiences of the person with dementia, in relation to her immediate surroundings. Central to the study are dementia-related psychological, sociological and gerontological concepts, re-interpreted in an architectural discourse scenario.

The results present data collected across 4 different countries: United Kingdom, Japan, Australia and Malta. These include a set of architectural plans that map the experience of different individuals on an average day in the care environment, with a focus on the behaviour afforded by different physical and social elements in the dementia care environment. The results highlight areas that are responsive to the needs of their residents, with the ultimate measure of success being an improvement in the quality of life of persons with dementia.

Indeed, recognition of non-pharmacological approaches such as the built environment in the treatment of dementia (Zeisel, 2012), coupled with the belief that each person is unique can cause the paradigm shift necessary for holistic person-centred care.

### **Keywords**

Design, outdoors, accessibility, cultural-appropriateness



## Leading the way: exploring creative arts initiatives led by and for people living with dementia

### **Dr Rose Capp**

Dementia Australia, Melbourne, Australia

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

There is a burgeoning body of research attesting to the benefits of involving people living with dementia in arts-related activities. Arts-related activities span a diverse range of creative forms and practices including music, painting, drama, dance and creative writing, and can involve varying levels of engagement from passive (listening to music) to active engagement (group singing or producing artworks). Studies have explored practitioner or therapist-led, co-designed or co-created arts-related activities in a range of settings from community-based participatory initiatives to programs and projects developed in residential aged care and other health care settings. Depending on the activity and level of involvement, the benefits for people living with dementia include cognitive and physical stimulation, social engagement, a sense of control and personal satisfaction, affirmation of identity and enhanced emotional and psychological wellbeing.

Drawing on recent findings highlighting the importance of 'in-the-moment' approaches and outcomes in arts-related activities, and the broader benefits of social engagement for the person living with dementia, their family members and carers, this paper will explore the significance of creative arts initiatives and projects led by people living with dementia. Developing findings from a 2023 Dementia Australia discussion paper on creative arts involvement, key examples of Australian, community-based participatory arts activities led by people living with dementia will be discussed. This paper will argue that in addition to the creative and other benefits, these initiatives are significant in the broader context of people living with dementia actively advocating for the services and supports required to promote their wellbeing.

### **Keywords**

Creativity, wellbeing, dementia, community-based, participatory



## Creating Memories – An Art Therapy Group Programme for Persons Living with Dementia in Long Term Care

Ms Shu Ning Poh, Ms Wan Xiang Lee

Ren Ci Hospital, Singapore, Singapore

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Background:** Art Therapy as a non-pharmacological intervention is increasingly recognized to have positive impacts on the well-being of Persons living with dementia. This study seeks to contribute towards the emerging literature in Asia and better inform healthcare providers of the benefits of a culturally appropriate Art Therapy programme to enhance the quality of life of Persons living with dementia and their care partners.

**Aim:** This study is a review of the 8-week structured Art Therapy: *Creating Memories* Group Programme designed for Persons with mild to moderate dementia or cognitive impairment in a long-term care setting in Singapore.

**Method:** The study discusses the impacts of this group programme that ran between 2018 and 2023 where 32 Persons with Dementia had participated.

**Results:** Preliminary qualitative and quantitative outcome measures demonstrated improvements to the overall well-being of participants. Pre and post-intervention questionnaires were administered where initial findings affirms the recovering of abilities and skills, encouraging a sense of playfulness through creative expressions, strengthening of personhood through life review and reminiscence, leading to better care outcomes from care partners.

Additionally, improvements to visuospatial perception, attention span and strengthening of family ties through a celebratory art show and outings to art gallery/park/neighbourhood whenever possible, were also observed.

**Conclusion:** Despite advancing limitations, a Person living with dementia is nevertheless a Person with an interior subjective world. In supporting one through the symbolic language of art, an alternative channel for communication can be opened up.

This study reflects the challenges of sustaining the benefits experienced during the short-term intervention in the long run, as its limitation. Due to the small sample size of the study, further explorations are required to support the efficacy of the introduction of Art Therapy as a supportive, non-pharmacological intervention to enhance and maintain the well-being of Persons living with dementia.

### **Keywords**

Art Therapy, personhood, well-being, non-pharmacological intervention, life review, reminiscence



## The right to rehabilitation for people with dementia: identifying barriers and solutions through co-design

Dr Natasha Layton<sup>1</sup>, Ms Catherine Devanny<sup>1</sup>, Ms Kate Swaffer<sup>2</sup>, Dr Angel Lee<sup>1</sup>, **Prof Michele Callisaya**<sup>1</sup> Monash University, Melbourne, Australia. <sup>2</sup>University of Wollongong, Wollongong, Australia

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Aims:** People with dementia have a human right to equal access to quality health care. Despite evidence regarding the effectiveness of rehabilitation to maintain function and quality of life, people with dementia experience inequitable treatment. To explore 1) barriers to access to dementia rehabilitation, and 2) to identify and co-design solutions that support and increase access to rehabilitation treatments.

**Methods:** Co-design methods were used with a sample of community-dwelling people living with dementia and care partners (n=13), as well as professional staff including clinicians, managers and dementia organisations (n=14) drawn from across Australia. Co-design principles (purposeful, inclusive, timely, transparent and respectful) underpinned both the approach and the strategies of engagement across a series of three virtual workshops. A socio-ecological analysis was applied to findings regarding barriers and solutions. This qualitative research was conducted in accordance with COREQ guidelines.

**Results:** Co-designers had high attendance (86-100%) at the principles-based co-design workshops which facilitated small group and whole group discussions. Barriers were identified at 1) a person level and categorised into their ability to a) engage, b) pay, c) reach, d) seek and e) perceive; and 2) a system level and categorised into a) appropriateness, b) affordability, c) availability, d) acceptability and e) approachability based on the Levesque Access to Health care framework. Solutions addressing the identified and modifiable barriers were co-designed.

**Conclusions:** Co-design is effective and empowering in identifying solutions to improve access to dementia rehabilitation with a variety of stakeholders. Including people with lived experience in co-design research work is epistemologically sound, ensures solutions meets the needs of people with dementia, and using a range of co-design principles and strategies can enhance this experience.

### **Keywords**

rehabilitation, co-design, stigma, allied health, human rights





# Re-envisioning What connects us\_Ce qui nous lie with and for persons living with Alzheimer's and related disorders and Carers: The impact of an intersectoral partnership on connectivity and loneliness

**Prof Melissa Park**<sup>1,2,3</sup>, **Ms Marie Christine Le Bourdais**<sup>4</sup>, Ms Sarah Piombo<sup>5</sup>, Prof Patricia Belchior<sup>6</sup>, Prof Thomas W. Valente<sup>5</sup>

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### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Aim:** The aim of this Public Health Grant of Canada: *Dementia Community Investment* was to collaboratively cultivate sociocultural environments worth living in by using shared activities/events to 1) link arts/culture, mental health, and academic institutions with community-based organizations working with persons living with Alzheimer's and their Carers; 2) create an enriched web of resources; and 3) help decrease stigma at the intersection of dementia, mental illness, and aging.

**Methods**. We used a participatory approach to cultivate an intersectoral partnership to identify desired activities and outcome measures and a mixed methods ethnography to evaluate and document both the process and effects of the project. Process evaluation included participant observations, supplemented by digital recordings and narrative interviews, to capture key moments of change over the two-year project that took place during the pandemic. Impact was assessed using a pre/post intervention social network survey for partner organizations and pre/post activity surveys for persons living with Alzheimer's and Carers that included the UCLA Loneliness Scale and CDC Quality of Life questionnaire.

**Results.** For the partner survey, community-based organizations became more centrally situated within the network with an overall increase in intersectoral reciprocity across organizations. For the persons living with Alzheimer's, Carers, and members of the public, participation in the dance/movement sessions, museum visits/art workshops, and film screenings resulted in significantly decreased experiences of loneliness, increased Quality of Life, and more positive sentiment about dementia.

**Conclusion.** Group activities hosted or sponsored by arts/culture organizations, in partnership with community-based organizations can effectively be used to re-envision dementia care in the community with far reaching implications into the everyday lives of persons living with Alzheimer's, carers and the organizations that work with them.

### **Keywords**

connectivity, loneliness, intersectoral, implementation, stigma, networks



### **Evaluation of an Intergenerational Singing Programme for Pre-Schoolers and Nursing Home Residents Living with Dementia**

#### **Ms Grace Low**

Esplanade - Theatres on the Bay, Singapore, Singapore

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Background:** As Singapore's national performing arts centre, Esplanade – Theatres on the Bay is guided by our mission to entertain, engage, educate, and inspire through the arts. Our community engagement programmes bring the arts to underserved communities. One such programme is *Sing Out Loud!*, developed with Dementia Singapore. Besides imparting basic vocal techniques, the programme seeks to stimulate emotional and memory recall through music reminiscence. For the first time since its launch in 2016, an intergenerational component was introduced in the 2023 edition. This report evaluates the impact of the programme on a group of pre-schoolers (n=9) and nursing home residents living with dementia (n=9).

**Methods:** Eight 1-hour workshops were conducted, culminating in a private graduation showcase at Esplanade attended by care partners, family members, and staff. Instead of self-reported data, observational reports were used to assess the impact of the programme on both participant groups. The staff completed questionnaires and structured interviews before, during, and after the programme. Observations of the pre-schoolers were based on the Leuven scale of involvement, while observations of persons living with dementia revolved around their verbal, behavioural, and social engagement.

**Results:** Despite the absence of a control group, the opportunity to learn how to sing together in an intergenerational setting appeared to increase engagement levels in both participant groups. When paired with someone from a different age group, participants were observed to be more confident in projecting their voices.

**Conclusions:** The success of the inaugural intergenerational edition of *Sing Out Loud!* highlights the potential of such arts-based interventions, although longer-term research studies can be considered to further understand its biopsychosocial impact on persons living with dementia.

### **Keywords**

intergenerational, dementia, children, music, singing





## **Best Practices for Hybrid Art Museum Programs for People with Dementia**

Ms Pooja Lalwani, Ms Sujal Manohar, Ms Jessica Kay Ruhle

Duke University, Durham, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

The *Reflections* program at the Nasher Museum of Art at Duke University offers art gallery tours for adults with dementia and their care partners. Originally an in-person program, *Reflections* adapted to a virtual model during the COVID-19 pandemic and now utilizes a hybrid model with in-person and online programs. Surveys distributed to *Reflections*' participants indicate the benefits of having both in-person and virtual options post-pandemic. Anecdotal survey data and participation statistics show high engagement and satisfaction with the current hybrid mode. Literature about hybrid art education programs for people with dementia remains limited. We offer best practices and insights for other museums and organizations interested in serving people with dementia through similar arts-based initiatives.

### **Keywords**

dementia, Alzheimer's, art museum, visual arts, virtual



## Nursing care of elderly patients with dementia and nurses' feelings during coronavirus disease (COVID-19) pandemic: A systematic review

**Dr Akiko Hamahata**, Dr Setumi Kudo, Ms Naomi Takahashi, Mr Masaki Abe, Ms Rika Kubo Osaka Seikei University, Osaka, Japan

### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

**Aims:** In Japan, many elderly people were hospitalized in acute care hospitals and some wards were converted into those for coronavirus disease patients. The aim of this study is to clarify nursing care of elderly patients and nurses' feelings during the COVID-19 pandemic.

**Method:** A systematic review was carried out using databases formulated in Japanese. Two researchers searched the literature separately, duplicate articles were deleted, and minutes, commentaries, reviews, and conference presentations were removed.

**Results:** Based on analysis of the details of 19 studies meeting the criteria, three themes were categorized: special consideration for elderly patients with dementia, managing restrictions on visits, and nurses' fear of infection. In eight studies, nurses' special consideration for elderly patients with dementia were to prevent infection, the progress of dementia, and isolation, and facilitate smooth communication. Restrictions on visits affected the elderly patients' mental and physical condition; however, nurses made it possible for the elderly patients to contact their families. Nurses' feelings were: fear of themselves and family members getting infected, fear of a collapse of the medical system, working with an unknown infectious disease, and work conditions. Most nurses were disappointed in their work because they could not care for patients as they had usually done prior to the pandemic.

**Conclusion:** Regardless of whether dementia was present, elderly patients were confused about restrictions on visits and infection prevention.



### Multi-stakeholder and Global approach to qualitatively assess what people with lived experience of dementia want policy-makers to do differently in future pandemics and/or crises

**Ms Rachel Louise Fitzpatrick**<sup>1</sup>, Dr Geeske Peeters<sup>2,3</sup>, Dr Tatyana Mollayeva<sup>3,4,5</sup>, Dr Yaohua Chen<sup>3,6</sup>, Prof Iracema Leroi<sup>3,7</sup>

<sup>1</sup>Trinity College Dublin, Dublin, Ireland. <sup>2</sup>Radboud University Medical Center, Nijmegen, Netherlands. <sup>3</sup>Global Brain Health Institute, Dublin, Ireland. <sup>4</sup>Toronto Rehabilitation Institute, University Health Network, Toronto, Canada. <sup>5</sup>Dalla Lana School of Public Health, University of Toronto, Toronto, Canada. <sup>6</sup>CHU Lille-University of Lille, Lille, France. <sup>7</sup>Trinity College Dublin, School of Medicine, Dublin, Ireland

### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

**Aim:** To determine what people with lived experience of dementia wish to be done differently in future pandemic and/or crises, as learned by the COVID-19 pandemic, taking a Global perspective across Europe and Latin America.

**Methods:** We distributed an online survey to people with dementia, family care partners and health care professionals (HCP) across five European (Ireland, United Kingdom, Netherlands, Greece, and Spain) and five Latin American (Brazil, Chile, Ecuador, Peru, and Colombia) countries, asking respondents to comment if they would like to see anything done differently should there be another pandemic. We qualitatively analysed responses using thematic analysis to come up with key themes.

**Results:** 151 people completed this survey (18 people with dementia, 62 care partners, 67 HCP, and 4 people who did not specify). There was much overlap between countries with regards to what respondents wished to be done differently in future pandemics. The top themes identified included: providing increased support for people with dementia and their carers to alleviate loneliness and mental health difficulties exacerbated by COVID-19 measures; allowing self-autonomy around one's own protection; and adopting more person-centered approaches.

**Conclusion:** These findings indicate the need for more flexibility in policy for people with dementia and their care partners in future pandemics or crises in order to balance personal needs against public health and safety needs, so as to avoid accelerated decline in health.



### The Impact of COVID-19 on Fathers with Dementia

### Miss Kublai Chiou

Dementia Center, Taipei City Hospital, Taipei, Taiwan

### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

During the COVID-19 period, as a dementia-related researcher, I observed the difficulties and cognitive deterioration my father encountered when suffering from COVID-19.

- 1. How do people with insufficient cognitive abilities learn various protective measures?
- 2. Reduce learning sources and external contacts after the base is closed.
- 3. How to plan distance teaching methods suitable for people with dementia
- 4. Suffering from COVID-19 causes a vicious cycle of loss of appetite, lack of physical strength and lack of exercise
- 5. Medical treatment that is emergency rather than preventive indirectly leads to the disability of the elderly.
- 6. Post-COVID-19, cognitive decline among most survivors

As my Paper in 2022 ADI (Ref.No E5-01-004), the father's inability to participate in the stronghold courses due to the epidemic caused accelerated cognitive decline, but unsuitable way for prevention and treatment of epidemic diseases and medical treatment also the reason?



## Large-scale exhibitions of children's drawings to change the narrative of old age and dementia

### **Dr Kasper Bormans**

Maastricht University, Maastricht, Netherlands

### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

**Aims.** Dementia and old age are overloaded with stigma and harmful connotations. The elderly are predominantly portrayed and perceived as depressed, lonely and dependent. The negative perspective encourages mutual avoidance behavior and confronts the elderly with a social death. It is beneficial for every society to look through the eyes of children at the challenges of the future in health care.

**Method.** In this study, we collected 796 children's drawings from 98 children of 10 years old from 6 elementary schools. Every child completed a 16-week educational trajectory with positive interventions to connect generations. Pre- and post-intervention, the children made portraits of elderly people and grandparents who are neutral, happy or unhappy. The drawings are implicit instruments for accessing and visualizing children's hidden perceptions of old age and dementia. The evolutions in the pre- and post-measurements demonstrate the mental landscape of children, and of society as a whole, is malleable and open to change.

**Results.** The artistic exhibition reached over 3000 visitors in 3 weeks and received a large quantity of national media attention. The unprejudiced viewpoint of children is able to change the narrative on dementia by delivering society a more constructive approach of the elderly, and people with dementia in particular. Children teach us to focus more on dignity, positivity and humanity.

**Conclusion.** This research indicates that the perspective of children can support the general public to nuance the negative view of old age and dementia. Positive qualities of children can be employed to lighten the burden of dementia for society.



The effect of a multi-component rehabilitation program on the cognitive function in older adults with dementia and older adults without dementia after recovery from COVID-19 in long-term care facilities.

Miss Suet-Lai Leung, Mr Yi-Lun Chan, Miss Po-Wah Wu Caritas-Hong Kong, Hong Kong, Hong Kong

### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

**Aims:** This study aims to examine the effect of a multi-component rehabilitation program on cognition in residents with dementia and residents without dementia after recovery from COVID-19 in long-term care facilities in Hong Kong.

**Methods:** Participants were recruited from two Care & Attention Homes in Hong Kong from July 2022 to February 2023. Inclusion criteria: (1) aged 65 or above, and (2) under isolation during the outbreak of COVID-19. Those who were unable to follow commands or were bed-bound were excluded. Participants were divided into three groups: (1) had a medical diagnosis of dementia and a history of infection, (2) had no diagnosis of dementia but had a history of infection, and (3) no diagnosis of dementia and history of infection. They all received a 12-week multi-component rehabilitation program designed by the Occupational Therapists after recovery from COVID-19 or isolation. The program comprised once-perweek sitting Ba-Duan-Jin and once-per-week individualized cognitive stimulting activities. MoCA 5-minute scores were compared across different time points: T0=premorbid, T1=post-isolation/infection+ isolation, and T2= post-rehabilitation.

**Results:** A total of 62 participants (female =43) were recruited with a mean age of 87.24 + 7.34. The Wilcoxon Signed-ranked test showed that MoCA 5-minute scores decreased significantly from T0 to T1 in all three groups (p =0.02 in group 1; p= 0.00 in group 2, and p= 0.01 in group 3). There was an increase in MoCa 5-minute mean scores from T1 to T2 in three groups: group 1 = 0.04, group 2= 1.05, and group 3 = 1.08. However, the changes were not statistically significant.

**Conclusions:** The study finds that a multi-component rehabilitation program may have a positive effect on the recovery of cognitive function in older adults after recovery from COVID-19 or isolation. The effect of treatment may be affected by the presence of dementia diagnosis.



# Neurological and psychosocial implications of COVID-19 pandemic in the elderly with and without a diagnosis of dementia: data from the Abbiategrasso Brain Bank.

**Dr Tino Emanuele Poloni**<sup>1,2</sup>, Dr Valentina Medici<sup>1</sup>, Dr Matteo Moretti<sup>3</sup>, Dr Silvana Damiana Visonà<sup>3</sup>, Dr Elena Rolandi<sup>4</sup>, Dr Stella Gagliardi<sup>5</sup>, Dr Chiara Calatozzolo<sup>1</sup>, Dr Orietta Pansarasa<sup>5</sup>, Dr Giulia Negro<sup>1</sup>, Dr Arcangelo Ceretti<sup>1</sup>, Dr Mauro Ceroni<sup>1</sup>, Dr Antonio Guaita<sup>1</sup>

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### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

**Aim:** To discover the neuro-behavioral, and psychosocial consequences of COVID-19 and their possible implications in the genesis of long-COVID.

**Methods:** Study 1: Retrospective analysis of 59 cases with dementia and COVID-19, conducted during the pandemic peak in 2020, to clarify the prognostic significance of delirium. Study 2: Neuropathological and transcriptomic comparison between 9 COVID-19 cases (with and without dementia) and 6 matched non-COVID controls. Study 3: telephone survey during lockdown, conducted on 204 cognitively assessed elderly.

**Results:** Study 1: Delirium was an onset symptom in 37% of cases and strongly associated with higher mortality (p<0.001), independently associated with an increased risk of mortality (OR:17.0-95% CI:2.8-102.7; p=0.002). Study 2: COVID-19 brains showed nonspecific hypoxic agonic changes, and a variable degree of pre-existing neuro-degeneration. The picture was dominated by hyperactivation of innate immunity (CD68-positive amoeboid microglia), while lymphocytes were scant with minimal antigenic traces of SARS-CoV-2 only in the brainstem, where microglial activation was higher (p=0.046). There were microglia increase in the hippocampus (p=0.048) of cases with delirium. The amount of viral RNA in the frontal cortex was minimal, detectable only by a very sensitive method (dd-PCR). The COVID-19 transcriptional signature in the brain shows reduction of the hypoxia inducing factor, with an increase in IncRNA CTB-36O1.7 (microglial modulator). Study 3: subjects with dementia were less able to adapt, and more depressed. Memory worsening occurred in dementia patients (p=0.006).

**Conclusions:** Long-COVID in elderly patients is not the result of a direct brain invasion by SARS-CoV-2, but derives from a complex interaction between biological and psychosocial factors.



### The Effects of COVID-19 Lockdown on Patients with and without Dementia

Dr Lana Alhalaseh, Dr Bayan Alkelani, Dr Hesham Aboushakra

The University of Jordan, Amman, Jordan

### **Topic**

Dementia as a public health priority: COVID-19 and dementia

### **Abstract**

### **Attached Tables**

**Background:** The relationship between loneliness, depression and dementia has gained attention post-pandemic. This study aimed to understand the relationship between loneliness, depression and dementia during the COVID-19 pandemic lockdown.

**Methods:** A descriptive study of community older adults with (n=94) and without (n=362) dementia who were able to communicate over the phone during the COVID-19 nationwide lockdown. The instrument included questions about sociodemographic factors, subjective health, functional status, and medical history. Patients were classified in the dementia group if they had a previous diagnosis or treatment of dementia. The screening three-item UCLA loneliness scale and the Geriatric Depression Scale were used. Questions about participants' feelings towards the pandemic and the curfew were also entered.

**Results:** Dementia patients were older than those without dementia (74.00  $\pm$ 7.80 vs. 72.09  $\pm$ 6.52, P = 0.030). They had significantly higher rates of functional dependence (P < 0.001), past history of depression (P < 0.001), multi-morbidity (P < 0.001), polypharmacy (P < 0.001), and poor subjective general health (P = 0.001).

Both groups experienced a statistically significant median increase in loneliness scores during the lockdown (P < 0.00), with dementia patients showing significantly higher means of loneliness scores before (P=0.001), and during the lockdown (P=0.02) and higher rates of depression especially moderate-severe.

Predictors of depression in dementia patients included loneliness and past history of depression. Non-dementia patients also had lower levels of education, poor subjective health and the fear of a COVID infection as predictors.

**Conclusion:** Dementia patients faced higher depression & loneliness rates during lockdown. Situational risk factors especially fear of the unknown disease did not impact dementia patients' depression risk. It is recommended that dementia patients should be considered at high risk for loneliness and depression no matter what situational changes are there. Measures to identify those patients in catastrophic states are essential to prevent the development of depression.





## A comprehensive review of National Dementia Plans: are human rights considered?

Miss Briony Harden, Prof Martin Orrell

Institute of Mental Health, University of Nottingham, Nottingham, United Kingdom

### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

**Background:** Despite the adoption and ratifications of the Convention on the Rights of Persons with Disabilities (CRPD), people with lived experience of dementia are subject to restrictions on their rights, such as the right to equal recognition before the law. As a result, countries have been encouraged to develop their own National Dementia Plans (NDPs) as part of the World Health Organization's (WHO) 'Global Action Plan on the Public Health to Dementia 2017-2025' (WHO, 2017). The action plan emphasises a rights-based approach in dementia, meaning plans should comply with and promote the CRPD principles.

**Aims:** The present study aims to evaluate how far the CRPD principles are reflected within the NDPs, such as community inclusion, dignity, and legal capacity.

**Methods:** A deductive content analysis will be used to comprehensively review the human rights content of global NDPs. We identified the plans through the Alzheimer's Disease International (ADI) and Alzheimer's Europe websites, and the WHO MindBank database. A standardised template and survey was developed to include specific CRPD principles, the WHO QualityRights categories, and other relevant rights including empowerment.

**Results:** We expect to finish the analysis by the end of November 2023. Early examinations show that the CRPD itself is not specifically mentioned in several NDPs, with several other rights mentioned in passing rather than as specific actions, including freedom from coercive practices.

**Implications:** The ADI recently called for the target deadlines to be extended due to a lack of countries developing NDPs. However, it is important to examine how far countries have followed the WHO's guidance to include human rights of people living with dementia within their plans. The findings of this study will be used to inform the ADI and the WHO as to how NDPs and policies can be more human rights-focused.



## Culturally-safe Dementia Care: An Emerging Global Health Policy Agenda

### Mr HOM Lal SHRESTHA

Laurentian University, Sudbury, Canada

### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

Culturally-safe dementia care (CSDC) is a novel and dynamic concept in the global health arena.

Access to CSDC is an emerging challenge globally as dementia remains a catastrophic public health crisis, despite being declared the seventh leading cause of death in the world. This paper aims to urge the World Health Organization (WHO) and international communities to accelerate CSDC as a global public health priority policy agenda. The WHO Dementia Plan Guide (2018) identified and documented traditional healers and community leaders as "community stakeholders" for dementia care and prevention worldwide. It is critical to develop a country strategy and plan, a policy framework, and evidencebased research for dementia care and prevention to support the implementation of the WHO Global Action Plan on the Public Health Response to Dementia (2017–2025). There is a lack of global political commitment and progression on policy, plans, and strategies for the recognition, engagement, education, empowerment, and reconciliation of the trajectory of traditional healers and community leaders as "community stakeholders" and healthcare providers for dementia care and prevention at the community level globally. The respectful engagement of traditional healers and community leaders as "gatekeepers" to healthcare providers underpins the bridge to closing the dementia equity gap. The CSDC strategy aims to empower and enhance the capacity of health care practitioners, traditional healers, and community leaders to launch CSDC through local community dementia advisory groups and councils. Furthermore, no one is leaving dementia behind in this aging world, and traditional healers and community leaders are inevitably at the forefront of dementia care and prevention globally. Thus, the political commitment of WHO 194 member states, and the global members of ADI and the World Dementia Council, is crucial to fostering diversity, equity, inclusivity, justice, and reconciliation for CSDC and has prioritized a keystone global health policy agenda.



Dementia is a public health priority, it is a Global Concern. Therefore, we need to stand and fight against dementia. World leaders should make it as an emergency disease that is affecting all ages; young, youths and old. The global index proved by World Health Organization (WHO). and other NGOs have.

### **Mr Paul Bannister**

Environment Protection Agency, Bo City, Sierra Leone

### **Topic**

**Dementia as a public health priority:** Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

Dementia is a public health priority, it is a Global Concern. Therefore, we need to stand and fight against dementia. World leaders should make it as an emergency disease that is affecting all ages; young, youths and old. The global index proved by World Health Organization (WHO) that lot of people are affected with dementia due to the following reasons, lineage, stress, sexual abuse, drug abuse, for old people their grandchildren looking low upon them and disturb their grandparents. Moreover lot of developing country does not even have social homes and psychological problem is a greater challenge for Africa. They youths of today are now engaged in drug abuse most especially in my country, Sierra Leone like kush, Tramadol, marijuana, etc. The government of Sierra Leone has established a structure call the one health platform that gear towards all health related issues in the country. As a country, there is need for more awareness friendliness, research, and innovation to fight against dementia. Our aim is to engage in more advocacy network to raise awareness raising to the citizens of sierra Leone. there is need for inclusiveness by involving civil society groups, Media (television, radio and news paper institutions, religious Leaders, Local Government, central Government, NGOs, women's group, youth groups, ministry of Health and sanitation and also mental health, social welfare, and any other partners in regards of their support.

The government of Sierra Leone have committed to prioritize mental health as a national concerns due to the number of increase of mental health in the country. our youths and old people are vulnerable in regards to dementia disease. there are lot of challenges that are affecting our people and there is need for immediate intervention if not by 2030 Sierra Leone will be in high increase of dementia due to following factors.



## Grassroots initiatives: Paving the way for sustainable dementia care policies in Brazil

**Dr Elaine Mateus**<sup>1</sup>, Prof Edson Leandro Minozzo<sup>2</sup>, Ms Thaissa Araujo de Bessa<sup>3</sup>, Ms Ana Karina Anduchuka<sup>4</sup>

<sup>1</sup>Febraz, Londrina, Brazil. <sup>2</sup>FEEVALE University, Novo Hamburgo, Brazil. <sup>3</sup>The State Department of Health of Rio Grande do Sul, Porto Alegre, Brazil. <sup>4</sup>The Department of Elder Affairs, Londrina, Brazil

### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

The Brazilian Senate passed a bill in November 2021 establishing the National Policy for Comprehensive Care for people living with dementia and care partners. However, almost two years later, in October 2023, the initiative remained stagnant in the Chamber of Deputies, indicating a lack of willingness to prioritize it. Despite this, local initiatives have emerged over the past four years, highlighting the significance of grassroots movements as successful practice models within communities. Notable examples include laws created by multiple stakeholders, comprising experts, collectives, researchers, journalists, families, and individuals diagnosed with dementia. These laws were approved in São Paulo and in the Federal District in 2021, as well as in the state of Rio Grande do Sul in 2022, reflecting successful engagement of multiple stakeholders.

We present two ongoing groundbreaking public health experiences at a local and state level. At the local level, it involves a Public-Private Partnership, where the Department of Elder Affairs of a city with 600,000 residents invests municipal resources in providing support and care services for people with dementia through the community-based organization, Forget-Me-Not Alzheimer's Association. At the state level, Rio Grande do Sul launched an Introduction to Alzheimer's Disease Course for primary care professionals as result of collaboration between State Department of Health and geriatrician Leandro Minozzo, coauthor of the National Health Plan, and also a member of the Steering Committee for the preparation of the State Plan for Comprehensive Dementia Care in Rio Grande do Sul. These experiences indicate more effective paths for the development and sustainability of public policies.

These experiences indicate more effective paths for the development and sustainability of public policies. Resources to investigate the effects of these initiatives are fundamental for feasibility and scalability analysis.



### Dementia care landscape in Nepal: Current situation and challenges

**Dr Madhur Basnet**<sup>1</sup>, Mrs Prekshya Thapa<sup>1,2</sup>, Dr Sandesh Raj Upadhyaya<sup>3</sup>, Dr Nidesh Sapkota<sup>4</sup>, Dr Kedar Marahatta<sup>5</sup>

<sup>1</sup>B. P. Koirala Institute of Health Sciences, Dharan, Dharan, Nepal. <sup>2</sup>Trinity College, Dublin, Ireland. <sup>3</sup>Trishuli Hospital, Bidur, Nepal. <sup>4</sup>Patan Academy of Health Sciences, Lalitpur, Nepal. <sup>5</sup>World Health Organization, Kathmandu, Nepal

### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

**Introduction:** National dementia care plan could hel guidethe organization of dementia related services nationally. Nepal government does not have a dedicated national dementia care plan yet.

**Objective:** This study was conducted to better understand the context, barriers and opportunities for improving dementia care, treatment and support and guide the national dementia care plan.

**Methodology:** This document review was carried out through the review of information available in the public domain such as scientific publications, project documents/reports, media reports and hospital records, annual reports published by the Department of Health Services (DoHS), and District Public Health Offices (DPHO), Demographic and Health Survey reports, Old age homes (OAHs) and other relevant government reports and firsthand information gathered from relevant stakeholders based on Strengthening Response to Dementia In-depth Situational analysis Topic Guide(Stride) and WHO situational analysis framework from 1st June-31st August 2023.

**Results:** Existing policies in Nepal do not sufficiently address the need of people living with dementia and their caregivers. In relation to health services, Government of Nepal offers financial subsidies to people diagnosed with dementia; however, there are multiple complexities in receiving the care. This includes unavailability of services, structural difficulties, financial constraints, low level of awareness, stigma and inadequate human resources specifically geriatrician, geriatric nurses and geriatric psychiatrists. The epidemiological and psychosocial burden of elderly health issues is not rigorously studied in Nepal and no natinal data on dementia prevalence available yet. The services and incentives available are also fragmented and scattered. Similarly, there are no any current interventions targeted to the caregivers of people with dementia.

**Conclusion:** Nepal does not have any national dementia care plan yet and there is immense need of concerted efforts, plans and policies to address the rising burden of dementia with increasing elderly population.



## Advancing the policy and research agenda for dementia through brain health diplomacy

**Dr Walter D Dawson**<sup>1,2,3</sup>, Dr Laura Booi<sup>4,5</sup>, Dr Maritza Pintado-Caipa<sup>1,6</sup>, Dr Maira Okada de Oliveira<sup>1,7,8</sup>, Ms Alejandra Davidziuk<sup>9</sup>, Ms Mayte Vergara-Manríquez<sup>9,10,11</sup>, Mr Alex Kornhuber<sup>1,9</sup>, Ms Natasha Spoden<sup>2</sup>, Dr Renata Kochhann<sup>12</sup>, Prof Ian Robertson<sup>4,9</sup>, Dr Márcia Regina Cominetti<sup>1,13</sup>, Dr Harris A Eyre<sup>1,9,14,15,16</sup>, Prof Agustin Ibáñez<sup>4,9,17,18</sup>

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### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

**Aims:** The Brain health diplomacy (BHD) framework seeks to influence the global policy and research agenda for brain health by bridging multiple disciplines to improve brain health outcomes including those specific to dementia. This multinational, multidisciplinary approach to policy and research can help to close gaps in dementia risk reduction, diagnoses, treatment, care, and support across countries and regions. The aims of the BHD framework are in close alignment with multiple elements of the WHO Global Action Plan on the Public Health Response to Dementia 2017-2025, in particular dementia as a public health priority

**Methods:** A recent BHD exemplar is the Brain Health Diplomat's Toolkit for the Latin America and the Caribbean Region (LAC). Launched in 2023, the Toolkit was developed and piloted with LAC regional and global stakeholders with expertise in brain health, diplomacy, and public health. Expert reviews (n=13) and an online survey (n=64) were conducted to assess Toolkit efficacy.

**Results:** The BHD Toolkit seeks to provide emerging leaders, and other professionals whose work intersect with brain health across the LAC Region and beyond, with the tools to practice BHD. The BHD Toolkit provides a tangible resource to apply BHD concepts to advocacy spanning work within countries to international agreements between nations to support brain health.

**Conclusions:** To leverage the BHD Toolkit and additional opportunities to scale BHD, including for brainfocused policies at the national and international level that will support people living with dementia and care partners, several approaches may be pursued. Formal agreements to include the measurement of cognitive function in national health systems or other brain health metrics should be considered along with global health commitments to brain health. These commitments will need careful development through priority setting partnerships and with key stakeholder input to ensure equity in resulting policies and programs.



## **Engagement of Care Partners in Shaping Dementia Policy: Perspectives from Three Countries**

Prof Sherril B Gelmon<sup>1,2</sup>, Dr Jennifer Bethell<sup>3,4</sup>, Ms Mary Warbelow<sup>5,6</sup>

<sup>1</sup>OHSU-PSU School of Public Health, Portland, USA. <sup>2</sup>GBHI Lived Experience Panel, Trinity College Dublin, Ireland. <sup>3</sup>University of Toronto, Toronto, Canada. <sup>4</sup>EPLED (Engagement of People with Lived Experience of Dementia)/CCNA, Toronto, Canada. <sup>5</sup>Trinity College, Dublin, Ireland. <sup>6</sup>GBHI Lived Experience Panel, Dublin, Ireland

### **Topic**

**Dementia as a public health priority:** Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

Representatives from three countries will speak to policy issues regarding support of care partners of people living with dementia (PLWD). This conversation aligns with two themes of the WHO Global Action Plan on the Public Health Response to Dementia 2017-2025: 1) Empowerment and engagement of people with dementia and their carers, and 2) Universal health and social care coverage for dementia.

The first theme emphasizes empowering and involving PLWD and their care partners in "advocacy, policy, planning, legislation, service provision, monitoring and research of dementia". Simply put, the policy process should embrace "Nothing about us without us".

The second theme raises the crucial issue of universal health coverage. The first issue related to this theme is the lack of universal health coverage in developed countries such as the United States. The second issue, even in countries with such coverage, addresses ensuring equitable access and providing coverage to ensure protection of individuals against financial risk. Policy barriers exist in many countries which means that there are no guarantees that PLWD and care partners can access the "broad range of promotive, preventive, diagnostic and care services".

This session will also articulate issues relevant to ADI's "What's Your Plan" campaign, which emphasizes creation of national dementia plans, and coordination among key interested parties at federal and local government levels. Opportunities exist for PLWD and their care partners to participate in the policy process, and build upon their lived experience of both facilitators of, and barriers to, navigating the complicated spectrum of services and supports for PLWD.

The speakers represent people with lived experience and dementia researchers in Canada, Ireland, and the United States. Three speakers are proposed; other speakers may be added/substituted who are care partners or PLWD when it is clarified who is able to attend the ADI conference.



# Public health activities for persons living with dementia and their care partners in the Emilia-Romagna region of Italy as an example of good practice in patient care.

Mr Mateusz Cepielik<sup>1</sup>, Prof Andrea Fabbo<sup>2</sup>, Prof Dominik Olejniczak<sup>3</sup>

<sup>1</sup>College of Medical Sciences, University of Rzeszów, Rzeszów, Poland. <sup>2</sup>Cognitive Disorders and Dementia Unit at Health Authority and Services of Modena, Modena, Italy. <sup>3</sup>Chair and Department of Public Health, Medical University of Warsaw, Warsaw, Poland

### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

### **Abstract**

**The Aim** of this study was to gain an understanding of public health measures for persons living with dementia and their care partners being undertaken in the Emilia-Romagna region of Italy.

**Material and Methods:** The study was conducted in the Emilia-Romagna region of Italy, utilizing documentation analysis as the research method. The review included nine documents, including brochures, reports, guidelines, and handbooks published by public health institutions, local government, and non-governmental organizations between 2017 and 2021.

**Results:** In Emilia - Romagna, in Italy, there are various medical and social professions involved in legally regulated activities for persons living with dementia and their care partners, and a diverse range of support network services are available. From the moment of diagnosis of the condition until the terminal phase, the patient and his caregiver are monitored by Centers Cognitive Disorders and Dementia. Psychosocial activities are based on using, supporting and building the resources of the diagnosed with dementia and caregivers. An important function is also related to building social awareness, fighting stigmatization and social inclusion.

**Conclusions:** Legally regulated, interdisciplinary and holistic care results in uniformity and effectiveness of the social and medical support system and may translates into an improvement in the quality of life of persons living with dementia and their care partners. It also may slow down the development of the disease, prolongs the patient's independence, delays the process of institutionalization, and reduces the level of psychophysical stress among caregivers. Building social awareness of dementia and combating stigmatization may result in increased detection of the condition, reduce the negative impact of the condition and the accompanying disability on both patients and their carers, and can bring economic benefits in terms of reducing the cost of care to the state.



#### P2-009

### The time for an updated dementia strategy is now: Post-pandemic lessons from the current gaps in Canada

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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

**Aim:** Sixty-five percent of World Health Organization Member States lack a dementia strategy, and existing national strategies often do not address post-pandemic challenges for people with dementia (PLWD). In some Canadian regions, community-based care (aging at home and in the community) needs post-pandemic adaptation. Our review of Canada's jurisdictional approaches identifies gaps and focal areas for synergy and informs a global dementia strategy.

**Method:** We conducted a multimethod knowledge synthesis that included insights from a post-pandemic consultative session with Canadian public health stakeholders and an analysis of 114 documents. These documents comprised 28 Canadian and international policy reports, 25 project profiles, 10 evaluation reports across Canada, and 51 materials from the Alzheimer Society of Canada and the Public Health Agency of Canada websites. Our analysis involved content analysis using NVivo 14, with codes applied deductively.

**Results:** Our analysis underscored the gaps stemming from jurisdictional disparities in interpreting and implementing the federal dementia strategy. Stigma, age-related biases, limited resources in rural areas, and the absence of electronic health records further exacerbated these gaps. To bridge these divides, we identified five focal points for a global post-pandemic dementia strategy: community-based dementia care programs, dementia-friendly housing, and community philosophies, integrated electronic health records, home-support technologies (including monitoring and security systems), and well-defined compensatory financial system for PLWD and their caregivers.

**Conclusion:** We require an effective global post-pandemic dementia strategy for aging at home and in the community. A viable strategy consists of rapidly replicating multidisciplinary dementia care, bridging the gaps in the cost and quality of dementia-friendly housing, an integrated health records system, culturally and ethically supportive technologies, and a comprehensive, inclusive compensatory system for PLWD. These important aspects can strengthen the development of an updated dementia strategy.



#### P2-010

### Strengthening research capacity and policy responses to dementia in Romania (CREDEM)

**Dr Raluca Sfetcu**<sup>1</sup>, Prof Catalina Tudose<sup>2</sup>, Dr Tiberiu Ionescu<sup>2</sup>, Dr Daciana Toma<sup>2</sup>, Dr Stefania Ilinca<sup>3</sup>
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#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

In Romania, the challenges of neuro-cognitive diseases have so far received no recognition in the policy discourse and no national policies or plans addressing dementia exist. Currently, the Romanian Alzheimer Society is the only organization that recognizes the importance of developing coherent national policies for dementia and lobbys for the development of a national plan. The aim of the this poster presentation is to present the interim results of the Strengthening research capacity and policy responses to dementia in Romania (CREDEM) project which is currently being implemented in Romania.

The CREDEM project focuses on mobilizing and strengthening local resources in order to produce culturally, socially and economically contextualized analyses and develop locally tailored dementia responses. The process aims to identify the current situation, shared aspirations for the future and necessary steps towards achieving them. More specifically the projects will develop a simulation model of dementia care needs, the services required to meet them and the associated costs over the next 15 years. These will include workforce requirements (labour supply gaps, retention strategies, training and skills), financing and organisational barriers and opportunities to improve dementia care within the wider context of health and long-term care system reforms.

We will present the CREDEM process we designed for building stakeholder support for the development of a national dementia plan with a focus on the rapid situational analysis (providing a broad overview of the dementia situation in Romania) we conducted as well as the results of a Theory of Change workshops. We argue that CREDM is a good example for multi-stakeholder and evidence-based advocacy approaches to promote meaningful policy change.



#### P3-001

#### Inequalities in Dementia in England, Wales and Northern Ireland: Unveiling the Current Evidence and Developing Measures to Quantify Them

Ms Sian Besley<sup>1</sup>, Ms Helen Hayes<sup>1</sup>, Ms Patricia Cubi-Molla<sup>1</sup>, Ms Martina Garau<sup>1</sup>, **Dr Iain Hartnell**<sup>2</sup>

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#### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

#### **Abstract**

People living with dementia and their carers face many inequalities. However, despite inequalities in general being frequently on the agenda of decision-makers, there is relatively little consideration of inequalities in the context of dementia.

This research provides an overview of the inequalities faced by people living with dementia and their carers discussed in the literature. Four identified inequalities were then used as case studies to assess how inequalities could be measured using data from England, Wales and Northern Ireland.

#### These related to:

- deprivation and access to diagnosis,
- rurality and access to diagnosis,
- ethnicity and experiences of diagnosis,
- carers and the financial pressures of funding care and/or leaving work to provide care.

The literature review identified 110 inequalities experienced by people living with dementia in relation to their access to and experience of health and social care. These inequalities were between individuals living with dementia, as well as compared to people living with other diseases, and people in the general population. 28 inequalities experienced by carers were found.

English data on deprivation and rurality were sufficient to measure these, however, measuring diagnosis relied upon estimates of dementia prevalence based on old and unreliable data. Data on the ethnicity of people living with dementia in England was not sufficient to be reliably measured. Surveys of adult carers provided data to calculate the proportion of carers facing financial pressures in England – but this data lacked depth. It was not possible to measure any of the four inequalities in Wales and Northern Ireland, due to insufficient data availability.

In addition to highlighting the inequalities faced by people living with dementia and their carers, this research demonstrates the shortfalls in data collection around dementia. These limit understanding of the inequalities and so the ability of decision-makers to effectively tackle them.



#### P4-001

#### US dementia care spending by state, 2010–2019

**Dr Amy Lastuka**, Mr Michael Breshock, Ms Vivianne Swart, Dr Joseph Dieleman Institute for Health Metrics and Evaluation, Seattle, USA

#### **Topic**

Dementia as a public health priority: Economics of dementia

#### **Abstract**

**Introduction:** Dementia is the fourth largest cause of death for individuals over 70 years of age in the United States, and it is tremendously costly. Existing estimates of indirect costs of dementia are dated and do not report on differences across the US.

**Methods:** We used data from multiple surveys to create cost estimates and projections for informal dementia caregiving at the US state level from 2010 through 2019.

**Results:** In 2019, the annual replacement cost of informal caregiving was \$44,438 per prevalent case, and the foregone wage cost was \$20,373 per prevalent case. In 2019, it would have cost \$241 billion to hire home health aides to provide all of this care. If past trends persist, this is expected to grow to \$414 billion per year by 2050.

**Discussion:** The cost of informal care varied substantially by state and is expected to grow through at least 2050.



#### P5-001

### The Current Status of Promoting Dementia-Friendly Workplaces in Taiwan

Ms Elaine Ee Ning Chan, Mr Chin-Yuan Lin, Ms Yun-Ching Chen, Ms Li-Yu Tang

Taiwan Alzheimer's Disease Association, Taipei, Taiwan

#### **Topic**

Dementia as a public health priority: Employment, labour laws and dementia

#### **Abstract**

With the increasing number of people with dementia in Taiwan each year, there is also a gradual rise in the number of people with young-onset dementia, aged between 45-64, who could still contribute to the workforce. To encourage Taiwanese companies to retain capable people with young-onset dementia in the workforce, the Taiwan Alzheimer's Disease Association (TADA) has been advocating through seminars, forums, promotional materials, and other means over the past five years.

In addition to raising workplace awareness, the publicity program also brings in the perspective of a friendly environment and treatment. It enables participants to better recognize warning signs of dementia in their colleagues and equips them to provide assistance or information when needed.

As of October 2023, we have conducted over 80 sessions with more than 5,000 participants. These sessions have encompassed various industries, including state-owned enterprises and government agencies.

We have also been exploring more diverse approaches, such as organizing executive forums, essay competitions, online educational programs, microfilm productions, and other methods, to promote the importance of dementia-friendly workplaces.

We hope that through a series of efforts in the future, we can increase the employment rate of people with young-onset dementia. This not only helps them sustain their income but also postpones functional deterioration through social interaction. It ensures the rights to work of people with dementia, enables dementia families to access superior caregiving resources, and reduces the societal cost of care.



#### P06-001

#### A Study of Knowledge on Alzheimer's Disease and Attitudes of Chinese Social Residents towards Alzheimer's disease: a crosssectional survey in China

#### **Prof Jing Jiang**

Beijing University of Chinese Medicine, Beijing, China

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

**Abstract objective:** Social residents become increasingly concerned about Alzheimer's dementia (AD) as a global public health crisis. China's AD population is the largest and growing fastest. However, no study has examined Chinese social residents' knowledge and attitudes concerning Alzheimer's illness. This study examined Chinese social residents' AD knowledge and attitudes using the ADKS and DAS.

**Study design:** Cross-sectional survey. 338 social residents over 18 from various Chinese regions were recruited using convenient sampling.

**Method:** The Alzheimer's Disease Knowledge Scale (Chinese) and the Dementia Attitude Scale (Chinese) were used to assess their knowledge and attitude regarding AD.

**Results:** A total of 328 respondents (97.04%) completed the survey. ADKS =  $19.44\pm3.33$ ; DAS =  $86.98\pm12.7$ . Age and education level can have a substantial impact on ADKS scores, and education level can have a substantial impact on DAS scores.

**Conclusion:** The results indicate that China should implement comprehensive AD education for its social residents.



#### P6-002

#### "Let Me See if I Can Help": Dementia-Sensitive Participation in the Development of Technology for the Care of People Living With Dementia

Mrs Patrizia Held, Ms Ulrike Lindwedel

Furtwangen University, Furtwangen, Germany

#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

**Aim:** People living with dementia stand to benefit significantly from digital technologies, yet their integration into dementia care remains limited. The shortcomings often arise due to a lack of involvement of the target group in research projects. The project DIDEM seeks to address this gap by exploring how participatory research can be integrated into technology development, with people living with dementia actively engaged as co-designers.

**Method:** This study employs diverse methodological approaches and tools in participatory technology development, customized to meet the unique needs of people living with dementia. Regularly conducted co-design workshops involving participants from three care facilities serve as the primary data collection method, forming the basis for the development of a dementia-sensitive participation model.

**Results:** Preliminary findings indicate that even individuals in the middle stages of dementia can actively contribute to the design of technology aimed at enhancing their care and well-being. To facilitate meaningful participation, the model emphasizes the importance of: a) employing accessible methods based on familiar tasks that encourage creativity and engagement, b) fostering a dementia-sensitive attitude among all project stakeholders, characterized by flexibility and recognition of contributions, c) creating supportive conditions through strong relationships with gatekeepers and practical dementia expertise among researchers, and d) adopting a dementia-sensitive understanding of participation that places the focus on possibilities rather than limitations.

**Conclusion:** Involving people living with dementia in the development of care technologies represents a vital step toward creating a more inclusive and compassionate healthcare landscape. The dementiasensitive approach to participation underscores that participation should not be confined to existing models but should be adaptable to individual needs and preferences. By doing so, we not only advance technology-enabled care for people living with dementia but also promote their social inclusion and empowerment through active engagement in research and innovation.



#### P6-003

### Learning from "Expert by Experience": Knowledge Library of People with Dementia and The Dementia World Travel Guide

Prof Satoko Hotta<sup>1,2</sup>, Dr Yusuke Kakei<sup>3,2</sup>

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#### **Topic**

**Dementia as a public health priority:** Engaging people with dementia and carers in advocacy, policy and research

#### **Abstract**

In 2018, we collaborated with people with dementia, their families and supporters, community members, healthcare, long-term care, and welfare professionals, businesses, municipalities, relevant ministries and government bodies, researchers, and many others to launch the "Designing for Dementia Hub." With our sights set on creating "a future where people can live well with dementia," we are working together and taking actions based on the feelings, experiences, and knowledge of people with dementia.

One of our key activities is conducting interviews to people living with dementia. Through these we learn from "experts by experience" what the world of dementia is like. We gain insights into what they want, the challenges they face, and effective ways to live with those challenges. Working with experts in design, we sort the experiences and challenges mentioned in the interviews into different spheres of life so that anyone can easily understand them as "relevant to me."

Through hundreds of interviews to people with dementia, we recognize that they understand what they "can do", "can not do" and sometimes create their own coping strategies, such as "I go for walks with my dog, because dogs always know the way back home".

It is also inspiring to find many of them talked about little things that bring joy to their daily lives. In listening to their stories, we also discovered a couple of their secrets to being able to enjoy such pleasures.

Learning and visualizing their experiences, challenges and perspectives promotes dialogue between people with dementia and those around them and help improve environment. We have been producing Knowledge Library and the Dementia World Travel Guide based on the continuous interviews in Japan, it would be nice if we could learn from "expert by experience" globally.



#### Bending the Dementia Growth Curve: A Framework for Prevention, Symptom Deceleration and Reversal at all Leves of Healthcare Systems

#### Mrs Camille Nicola Isaacs Morell

Ville Saint-Laurent (Montréal), Ville Saint-Laurent (Montréal), Canada

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

The unrelenting growth in the number of persons living with dementia impacts every aspect of life worldwide, presenting significant challenges to public healthcare systems worldwide.

The total estimated worldwide cost of dementia was US\$ 818 billion in 2015, which represented 1.09% of global GDP at that time. The annual global cost of dementia is now above US\$ 1.3 trillion and is expected to rise to US\$ 2.8 trillion by 2030.[i]

There is a race against time to minimize the growth trends to achieve a more sustainable level of care and cost worldwide. This can be accomplished if the number of new diagnoses is reduced through proactive risk mitigation strategies and therapies that aim to alleviate and decelerate symptoms at all levels of healthcare systems worldwide.

The presentation will outline a framework that integrates strategies for the prevention, deceleration, and reversal of symptoms in the primary, secondary and tertiary levels of healthcare systems and proposes services that should be delivered cost effectively.

By focusing on disease prevention and health protection strategies, countries can aim to reduce the growth in the number of persons diagnosed with dementia and therefore better align their healthcare resources and systems with predicted care requirements in the future.

[i] Alzheimer's Disease International - Dementia in statistics Accessed 22 September 2023



### Projecting the potential impact of disease modifying therapy on the future health and social costs of Alzheimer's disease

Dr Dominic Trepel<sup>1</sup>, Dr Sophie Edwards<sup>2</sup>, Prof Craig Ritchie<sup>3,4</sup>, Dr Julie Hviid Hahn-Pedersen<sup>5</sup>, Mr Jamie Kettle<sup>6</sup>, Dr Mei Sum Chan<sup>6</sup>, Dr Ben Bray<sup>6</sup>, Dr Alice Clark<sup>5</sup>, Ms Milana Ivkovic<sup>5</sup>, Mr Christian Ahmad Wichmann<sup>5</sup>, Dr Marc Evans<sup>7</sup>, **Mr Niels Juul Brogaard**<sup>5</sup>

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#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

**Aims:** To model scenarios exploring a range of potential impacts of disease-modifying treatments (DMTs) for Alzheimer's disease dementia (ADD) on health and social care costs in the UK.

**Method:** A cohort Markov model was developed using UK population projections and prevalence data across five health states (cognitively unimpaired, mild cognitive impairment due to AD, and mild, moderate, severe ADD). Stage-specific transition rates and health and social care cost data were applied to estimate cost outcomes from 2020-2040. Treatment rates and follow-up care models (primary vs specialty care follow-up) were elicited from expert opinion. Scenarios combined ranges of DMT efficacy estimates, access (% of eligible population receiving treatment) and care models.

**Results:** Without DMT access, ~1 million people (1.5%) were projected to have ADD in the UK by 2040. Under the various DMT access scenarios, a reduction of 34k-98k ADD cases by 2040 was estimated, and the associated cumulative health and social care cost savings were  $\pounds$ 4.4–12.9bn over 2020–2040. Assuming a DMT treatment efficacy of 25%, raising DMT access from 25% to 58% led to cumulative cost savings increasing from  $\pounds$ 4.4bn to  $\pounds$ 10.1bn by 2040. Estimated cost savings were much higher in scenarios where the majority of patients received primary care follow up instead of specialist care follow up (e.g.  $\pounds$ 10.1bn, vs  $\pounds$ 0.4bn respectively by 2040).

**Conclusions:** These results indicate that high DMT access levels could substantially reduce the burden on patients and healthcare systems and emphasise the importance of early diagnosis and healthcare system preparedness.





# Gaps and Strategies to Strengthen Health Facility Level Non-Communicable Diseases Control and Management in Western Uganda: The Uganda Non-Communicable Diseases Alliance (UNCDA) and International Cancer Institute (ICI) Strategic Partnership Model

**Mr Christopher Kwizera**<sup>1</sup>, Ms Victoria Namata<sup>2</sup>, Dr Noleb Mugisha<sup>3</sup>, Ms Gloria Kitur<sup>4</sup>, Mr Kevin Makori<sup>4</sup>, Dr Chite Asirwa<sup>4</sup>

<sup>1</sup>Uganda NCD Alliance, Kampala, Uganda. <sup>2</sup>Uganda Non-Communicable Diseases Alliance, Kampala, Uganda. <sup>3</sup>Uganda Cancer Institute, Kampala, Uganda. <sup>4</sup>International Cancer Institute, Nairobi, Kenya

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

**Introduction:** Uganda NCD Alliance in partnership with the International Cancer Institute in Kenya set to implement a project aimed at strengthening community awareness by reaching out to 150,000 community members and screening 36,000 people for diabetes, hypertension, cervical, breast and prostate cancers in three districts of western Uganda.

**Methods:** Using district health teams, 10 level 3 and four health facilities were identified where a baseline survey was conducted that revealed gaps in NCD control and management attributed to inadequate skilled health work force, insufficient screening equipment, medicines and supplies, and lack of Information, Education and Communication (IEC) materials. Nine of the ten selected facilities were supported with NCD screening equipment and supplies; 30 health workers and 40 Village Health Teams (VHT) linked to the 10 facilities were trained with IEC materials distributed by VHTs in the community and health facilities.

**Results:** In 2 months post-training, the monthly facility reports indicated that 985people have been screened for diabetes and hypertension, 62 for breast cancer and 122 for cervical cancer. Over 60,000 people have been reached through awareness campaigns and outreaches, and 1,200 IEC materials distributed in the community and health facilities.

**Conclusion:** Health facility level NCDs control and management capacity can be enhanced through strategic partnership approaches that provide capacity building opportunities for the health workforce in NCD care. Multi-sector collaboration would be the answer to building strong health systems that address challenges in NCD control



### Healthy aging metanalyses of risk factors across Latin America reveal large heterogeneity and weak predictive models

#### **Dr Agustin M Ibanez**

BrainLat, Santiago, Chile. GBHI, Trinity, Ireland

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

Most models of healthy aging are based on findings from the US and Europe. However, these models often do not apply to diverse, understudied, and heterogeneous populations. We conducted a metanalysis on the predictors of cognition and functional ability in healthy aging across Latin America (n=146,000 participants), and reviewed the different methodological approaches used. When considering multiple predictors, significant but heterogeneous effects were observed for cognition (OR = 1.20, p-value = 0.03, CI = [1.0127; 1.42]: z full = -8.39, P < 0.001, z half = -12.92, P < 0.001, power estimate = 99%, CI = [98.3%, 99%]; heterogeneity: I<sup>2</sup> = 92.1%, CI= [89.8%; 94%]) and functional ability (OR = 1.20, p-value = 0.01, CI = [1.04; 1.39]; z full = -8.42, P < 0.001, z half = -10.228, P < 0.001, power estimate = 99%, CI = [99%, 99%]; heterogeneity: I<sup>2</sup> = 93.1%, CI = [89.3%; 95.5%]). Specific risk factors had limited effects, especially on functional ability, with moderate impacts for demographics and mental health, and marginal effects for health status and social determinants of health. Numerous methodological issues such outliers, inter-country differences, and publication bias influenced the results. A subsequent systematic review identified problems with combined predictors, computational analysis, study designs, and multicentric comparisons. Taken together, the results emphasize the need for greater harmonization of national and regional research efforts for healthy aging, as the current approaches limit the reliability and applicability of findings to develop tailored programs in Latin America.



## Comparing health students' attitudes towards dementia and epilepsy and mental health disorders: Knowledge, Attitudes and Practices Study (KAPs) in Low- and Middle-Income countries (LMICs)

Dr Emilie Auditeau<sup>1</sup>, Dr Marion Vergonjeanne<sup>1</sup>, Dr Benjamin Calvet<sup>1,2</sup>, Prof Edgard Ngoungou<sup>1,3</sup>, Prof Dismand Houinato<sup>4,5</sup>, Dr Gustave Mabiama<sup>1,6</sup>, Dr Sedera Mioramalala<sup>1,7</sup>, Dr Luz Maria Moyano<sup>1,8</sup>, Prof Camilo Felix Gallegos<sup>1,9</sup>, Dr Noudy Sengxeu<sup>1,10</sup>, Prof Sina Ros<sup>1,11</sup>, Prof Pierre-Marie Preux<sup>1</sup>, Prof Farid Boumédiène<sup>1</sup>, **Dr Leslie Cartz Piver**<sup>1,12</sup>

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#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

In LMICs, the increasing number of people living with dementia, epilepsy or mental health disorders is a challenge for healthcare systems. The KAPS project evaluates knowledge, attitudes and practices of future doctors, pharmacists and nurses in LMICs. This communication focuses on attitudes because these disorders have in common the risk of stigmatization.

The KAPS project was developed in French, English, Spanish and Khmer. STROBE initiative for observational studies in epidemiology served for developing and standardizing study methodology. Students in their last year of medicine, pharmacy or nurse studies were invited to the KAPS project on their University campuses. Socio-demographic data and knowledge (K), attitudes (A), and practices (P) test answers were collected by a self-administered questionnaire linked to a database management system. Scores are expressed as a percentage of correct answers.

From February 2020 to March 2023, 1893 students from 8 LMICs participated: Gabon (161; 8,5%), Benin (196; 10,4%), Cameroon (350; 18,5%), Madagascar (146; 7,7%), Ecuador (215; 11,4%), Peru (26; 1,4%), Laos (306; 16,2%) and Cambodia (493; 26%). Average age was 24,5 +/- 4,9 years old. Most students (80%) declared training in these subjects. 73% declared little information. 58% had been in contact with a person living with these disorders. Total attitudes scores were 77% correct, but dementia attitude scores (73%) were significantly lower than attitude scores in epilepsy (78,6%) or in mental health disorders (80%) (p < 0,0001). Students with no training scored significantly lower (73,8% versus 78,4%, p < 0,0001). Being little informed versus well informed had no effect. Having been in contact with a person living with these disorders increased the attitude scores (78,5% versus 75,9%, p=0,004).

**Discussion:** This original study suggests that dementia may be more stigmatizing than epilepsy and mental health disorders. Special attention is needed in dementia training of healthcare students in LMIC.



### Caring for people living with dementia and their informal caregivers: Current perspectives in Malaysia

**Miss Ken Joey Loh**<sup>1</sup>, Prof Alvin Lai Oon Ng<sup>1</sup>, Prof Yook Chin Chia<sup>1</sup>, Dr Wan Ling Lee<sup>2</sup>, Dr Devi Mohan<sup>3</sup>, Prof Elil Renganathan<sup>1</sup>

<sup>1</sup>Sunway University, Petaling Jaya, Malaysia. <sup>2</sup>University of Malaya, Petaling Jaya, Malaysia. <sup>3</sup>Monash University Malaysia, Petaling Jaya, Malaysia

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

With the declaration of dementia as a global health crisis by the World Health Organisation, this perspective paper seeks to shed light on the critical issue of dementia care in Malaysia, an upper-middleincome country. As Malaysia is rapidly becoming an ageing population, significant challenges faced by people living with dementia (PLWD) and their informal caregivers (ICs) in the nation need to be addressed urgently as a public health priority (Action Plan 1). The paper first outlines several factors that pose major obstacles to dementia care in the nation. The underfunded public healthcare system presents a major roadblock in treatment accessibility due to limited resources for elderly healthcare in public facilities. Affordability issues for the costly private healthcare present another roadblock to equal accessibility to healthcare. Moreover, the lack of investment in geriatric specialisation and training opportunities for healthcare professionals further hinders the development of multidisciplinary teams. Additionally, the absence of dementia-centric community health and support services for the PLWD and ICs, along with the lack of public education about dementia, also compound the problem. Taken together, these systemic gaps have far-reaching consequences not only on the PLWD, but also on the mental health of the ICs. Nonetheless, there is also a scarcity of evidence-based psychosocial support services for the ICs of PLWD in Malaysia to safeguard the mental health of ICs, as we describe in detail using the modified Stress Process Model. This underscores an urgent need for research and development in the area of supporting ICs of PLWD (Action Plan 5). This paper concludes with recommendations that align with Malaysia's national plans and policies, particularly in bolstering a skilled workforce for dementia care to prepare for current and future dementia care needs. Increased psychosocial interventions for the ICs are also advocated.



#### Qatar's Journey in Dementia Care - An Inspirational story of Leadership driving Qatar's Public Health Response to Global Action Plan

Dr Pravija Talapan Manikoth, Dr Irshad Badarudeen, **Dr Mani Chandran**, Dr Hanadi Al Hamad Hamad Medical Corporation, Doha, Qatar

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

A Journey that began about a decade back in Dept of Geriatrics , Hamad Medical Corporation , Qatar , a Country where stigma hindered anyone accessing care whatsoever for months together after opening the Memory Clinic. Leadership instilled with quality of perseverance to enhance care for Persons living with Dementia and support their care givers , inspired a care Journey that Led Person Living with Dementia , caregivers and stakeholders to come together making Qatar to become the first Arab Country to have a National Dementia Plan in November 2018 . Now having 12 Clinics per week spread across Both Tertiary care and Primary Care , with Outreach services reaching out across the Country , with service access numbers reflecting stigma mitigation to some extent , with 654% increase in total New Patients and a total of 632% increase in Total Patients seen over 7 Year , the Continuing strides of Leadership Overcoming Challenges , got Recognition from World Health Organisation making Dept of Geriatrics, Hamad Medical Corporation Qatar to become WHO Collaboration Centre for Healthy Ageing and Dementia in March this year .

A Living Inspirational Journey, where Overcoming challenges actually crafted the Dementia Care landscape for the Country ,

Presentation will take through ,how the Journey began , how Qatar became the First Arab Nation to have a National Dementia Plan , How Leadership strides helping us in Overcoming Challenges across each of the Action Areas Including Public Health Priority , Awareness and Friendliness , Risk reduction , Diagnosis Treatment care and support , support for Dementia carers , Information systems , Research and Innovation . A page from Leaderships Role in Dementia Journey , inspirational roadmap in enhancing Dementia care .in a Country .



Health System Preparedness for the early detection of Alzheimer's in Scotland and Mexico. Challenges and learnings from a pilot project including digital cognitive assessment (DCA) and blood based biomarkers.

Dr Mariana Lopez-Ortega<sup>1</sup>, Prof Alison McKean<sup>2</sup>

<sup>1</sup>National Institute of Geriatrics, Mexico Clty, Mexico. <sup>2</sup>Alzheimer Scotland, Dumfries, United Kingdom

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

We will present the main challenges experienced in the implementation of a pilot project to increase health system's preparedness for early detection of Alzheimer's by introducing digital cognitive assessment and blood-based biomarkers. The pilot projects were part of the Davos Alzheimer's Collaborative. For both countries, this was the first opportunity to include these tools as part of usual primary care. Two general practices (GP) in Dumfries and Galloway, Scotland and four primary care clinics in Mexico City, Mexico participated. In Scotland, GP practices are part of the National Health System, Scotland's public universal health care system, and in Mexico, clinics are part of Mexico-City's Ministry of Health, which covers those that are not affiliated with a social security institution (employment-based), are unemployed, or self-employed.

In Scotland the work was carried out as Quality Improvement and in the primary care settings involved general practitioners and health care assistants. The focus was on patients presenting with concerns about cognition or if this was identified during consultation. The blood test element was carried out within the specialist services. In Mexico, the work was carried out as a pilot to introduce an integrated evaluation for adults 60 years and older. Practitioners included General physicians, nurses and social workers, blood tests were carried out by the National Institute of Geriatrics.

In both countries, pre-program training sessions were held with HCPs who in addition answered two questionnaires (some were interviewed) to assess their knowledge of and perceptions towards dementia care practices in their daily work environment, at the beginning and end of the pilot. While both systems are different in coverage, financing mechanisms and resources, similar challenges emerged throughout the pilot's implementation process and this will be shared demonstrating the value of working and learning together on a global scale.



### Incidence and types of adverse events among people living with dementia in hospital settings globally: Scoping review

Mrs Lucía Catalán<sup>1,2</sup>, **Dr Déborah Oliveira**<sup>3,4</sup>

<sup>1</sup>Universidad Andrés Bello, Faculty of Nursing, Santiago, Chile. <sup>2</sup>Universidad San Sebastián, Faculty of Healthcare Sciences, Santiago, Chile. <sup>3</sup>Universidad Andrés Bello, Faculty of Nursing, Viña del Mar, Chile. <sup>4</sup>Millenium Institute for Care Research (MICARE), Santiago, Chile

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

**Aim:** People living with dementia are two times more likely to be admitted into hospital compared to people without dementia. However, little is known about the safety of their care in hospital settings. The aim is to establish the incidence and the most common adverse events suffered by people living with dementia in hospital settings globally.

**Method:** A scoping review was carried out in line with Arksey and O'Malley's (2005) framework in October 2023 in PUBMED, Web of Science, CINAHL, and SCOPUS. Primary peer-reviewed studies in English, Spanish, or Portuguese in 2012-2023 were included. Data extraction is currently underway. The methodological quality will be assessed using the Mixed Methods Appraisal Tool.

**Results:** Of 2,014 publications, 19 were included. These are retrospective (n=10), prospective (n=6), and cross sectional (n=3) in design. We found three distinct foci: 1) assessment of dementia as a risk factor for adverse events; 2) types and incidence/prevalence of adverse events; and 3) negative outcomes following hospitalization. Preliminary data show that common adverse events include falls (with or without a fracture) and medication side effects, which appear to lead to higher odds of having delirium, longer hospitalization, malnutrition, severe sepsis, acute respiratory dysfunction, dysphagia, hospital readmission, and death (during or after hospital stay). These are more likely to happen to people with dementia, compared to those without dementia.

**Conclusion:** The full set of results, conclusions, and recommendations will be presented at the conference.



#### P08-001

#### A Survey on Dementia Awareness in a Metropolitan Area in Taiwan

Mrs NAI YU LIN<sup>1</sup>, Mr Chien-Liang Liu<sup>2</sup>, Mr Hung-Meng Huang<sup>2</sup>

<sup>1</sup>TAIPEI CITY HOSPITAL, TAIPEI, Taiwan. <sup>2</sup>Taipei City Hospital, TAIPEI, Taiwan

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Purpose:** Understand about the dementia awareness survey of Taipei citizens.

**Method:** A 10-question questionnaire was used to investigate the general public's literacy of dementia in 12 administrative districts of Taipei City.

**Result:** In 2022, we conducted a dementia literacy survey in the 12 administrative districts of Taipei City. A total of 1,643 questionnaires were collected, including 716 males and 927 females, aged between 13 and 87.

- 1.83% of the populace do not know that dementia is not a normal part of aging
- 2.75% of populace believe that drug treatment can effectively treat dementia
- 3.80% of populace believe aggressive behavior by people with dementia is inevitable
- 4.78% of populace believe that the behavior of people with dementia is impulsive and unpredictable
- 5.95% know how to assist the lost and demented
- 6.92% of the populace know the measures to prevent getting lost, but they should reduce the chance of going out
- 7.71% of the populace believe that the initial manifestation of all types of dementia is forgetting things and forgetting things
- 8.72% of populace believe that people with dementia will have mental and behavioral problems
- 9.91% of the populace know that non-drug treatment can delay the progression of dementia
- 10.91% of the populace know that avoiding head trauma and maintaining good habits can prevent dementia

**Conclusion:** From this survey, it was found that there is a huge room for improvement in the dementia literacy of Taipei citizens, and it is still necessary to improve the literacy through continuous dementia publicity.



### Co-producing a boardgame to learn and engage about dementia inequalities

**Dr Clarissa Giebel**<sup>1,2</sup>, Dr Kerry Hanna<sup>1</sup>, Ms Hilary Tetlow<sup>2</sup>, Prof Mark Gabbay<sup>1,2</sup>, Ms Jacqui Cannon<sup>3</sup>

<sup>1</sup>University of Liverpool, Liverpool, United Kingdom. <sup>2</sup>NIHR Applied Research Collaboration North West Coast, Liverpool, United Kingdom. <sup>3</sup>Lewy Body Society, Wigan, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Background:** Receiving a diagnosis and accessing care after a diagnosis of dementia, both for the person and their carer, are fraught with inequalities. Finding different ways to address these inequalities is important. The aim of this public engagement activity was to co-produce a boardgame about dementia inequalities to facilitate learning, dialogue and educate about different barriers, and facilitators, to diagnosis and care.

**Methods:** Two virtual and two face-to-face workshops with people with dementia, unpaid carers, health and social care professionals, and Third Sector representatives were held between October 2022 and June 2023. The virtual workshops were split into discussions of inequalities and how a boardgame may feature inequalities. The first face-to-face workshop was split into the same activities, aided by outcomes from workshops 1 and 2. Workshop 4 attendees tested the prototype. Attendees were reimbursed for their time. Nine brief remote interviews with attendees were conducted to evaluate their experiences in the co-production of the boardgame.

**Results:** Forty stakeholders attended four workshops. Workshops provided step-by-step thoughts on how the game could be designed or modified. The final game, prototype tested in Workshop 4, consists of a one-sided, two-half board depicting the pre-diagnosis process (left half) and post-diagnosis process (right half). Interviews with nine attendees reported on their reasons for attending the workshops, experiences of being involved, and the game design and purpose.

**Discussion:** The game can be used to improve knowledge about dementia inequalities for health and social care professionals, carers, people living with dementia, decision makers, and general public.



### Perspective: Correlation between dementia awareness and fundraising

Mr Sherwan Sharip, Ms Cyndi Low

Dementia Singapore Ltd, Singapore, Singapore

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

In 2019, the Singapore charity sector recorded **\$3.25** billion in total donations. Dementia Singapore received only **0.001%** of that share.

After joining Dementia Singapore in 2020, I found that 90% of my network within the corporate circle including high-net worth individuals and philanthropists that I met have never heard of Dementia Singapore. Additionally, many of them knew very little of the condition, its impact on persons living with dementia and those around them.

This emphasizes the direct and strong correlation of dementia awareness and the motivation behind people's interest and willingness to donate and support the dementia cause. An effective outreach strategy is needed to improve the chances of increasing donations and achieving better outcomes in our fundraising efforts.

As early as 2021, Dementia Singapore pivoted towards initiatives not only raising funds but extended the outreach of awareness on dementia and its impact. From networking dinner, auction gala and charity golf, we successfully converted many non-supporters to donors through active relationship building as well as connecting with those who have connection to the condition. Although results were encouraging, the initiatives were limited by the audience we can reach out to. Equally important, we wanted to retain support from our current pool of supporters without the risk of donors' fatigue.

We ventured to organize our first-ever community carnival followed by a charity concert featuring Michael Learns To Rock. Tickets were sold out after 48 hours. The event attracted over 9,000 people, mostly new donors and repeat contributors supporting the cause.



#### Coffee with a Cop

#### Mr Norman Williamson

Alzheimer Scotland Active Voice, Glasgow, United Kingdom. Active Voice, Glasgow, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Nothing beats a good conversation over a cup of coffee and Scotland's two campaigning groups, the Scotlish Dementia Working Group and the National Dementia Carers Action Network , have adopted this adage in their effort to open a positive line of communication with Scotland's Police Force.

Both groups are member led with the SDWG representing people living with dementia; and NDCAN for carers of a person with dementia. The members recognise that communicating with the Police can often be a challenging and overwhelming experience for those affected by dementia. Now both groups are working to change that, and a recent collaborative venture saw them facilitating their first 'Coffee with a Cop' day. The aim was to bring the group members and others affected by dementia in the community, together with community police officers to discuss relevant issues and learn more about each other. The idea not only allowed the attendees to see the police are approachable, but also gave opportunity to raise awareness about dementia and discuss various initiatives that are available to help people live safely with dementia.

One unexpected outcome relates to Police Scotland's 'Dementia Safeguarding Tag' scheme - attendees had expressed their feelings that the term 'Tag' was inappropriate for this purpose and is an example of the negative language they are trying to eliminate when people talk about dementia. It was pleasing to note that Police Scotland have taken on board the feedback and have since involved the SDWG members in renaming this safeguarding scheme.



#### Partnership agreement with the National Gendarmerie

#### Mrs Lorène Gilly

France Alzheimer et maladies apparentées, Paris, France

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

In September 2022, the Director General of the National Gendarmerie, General of the Armies, Christian Rodriguez and the President of France Alzheimer et maladies apparentées, Joël Jaouen, decided to engage in a partnership to, on one hand, enrich the specific security offer implemented by the national gendarmerie for people living with Alzheimer's disease and their families and, on the other hand, to provide police officers caring for a family member living with dementia the support they need and to make sure they have acess to the expertise of France Alzheimer.

Thus, the convention includes numerous actions, such as the caregivers' training for police officers and their families affected by Alzheimer's disease. A first session will take place at the headquarters of the National Gendarmerie in 2023. Sessions can then be organized by videoconference.

A flyer will also be edited to help police officers to better understand the disease. Identifying the signs will thus allow them to enter into a relationship more easily with people living with dementia they may encounter and to adopt the right reflexes, for example by avoiding sudden injunctions.

A document will also be created for caregivers to encourage them to declare information to the gendarmerie prior to any kind of emergency situations. This would allow – in case of worrying disappearance for example - to have a "pre-informed form". This document would also be enriched with advice for caregivers in the event of a worrying disappearance, such as:

- not waiting before calling for help, given the kilometers of walking that can be done;
- avoiding putting your own fingerprints on clothing that will be entrusted to a canine squad.

Finally, connections will be facilitated throughout the territory between France Alzheimer's local branches and the Family Protection Centers set up in each department by the National Gendarmerie.



### The hunt for good moments – How to influence on and meliorate stigma about dementia amongst youngsters

**Ms Mina Gerhardsen**, Ms Tone Poulsson Torgersen, Dr Anne Rita Øksengård, Ms Ditte Staldgaard Norwegian Health Association, Oslo, Norway

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Background:** Norwegian Health Association is the national patient organization for persons with dementia (PWD) and their supporting carers.

Norway has 100,000 PWD, and around 400,000 persons are close relatives. In the public society many know little about what dementia is and how to deal with it. Many become uncomfortable encountering PWD. They regard dementia as shameful and do not know that it is caused by organic brain disease. The consequence is that PWD and their relatives experience isolation and loneliness. Little information about how to interact with PWD has been directed at youngsters.

Aim: The main objective was to achieve a more dementia-friendly society and reduce stigma.

The project: We created a documentary film about two families affected by dementia. Alongside the film, we developed tailored educational discussion tools for use in both school and family settings. Our ambition was that young people (aged 13 to 19) should learn to reflect on and discuss the consequences of dementia for the individual, the family, and society, as well as what they themselves can do to contribute to a more dementia friendly world. We reached out directly through information on social media.

**Results:** The film and the discussion tool are used in Norwegian schools. The feedback is that the film engages and promotes reflection, making young people more confident when encountering PWD and their care partners. The teenagers have gained more knowledge about dementia and could themselves act as "dementia influencers".

**Impact:** Youngsters who are next of kin to PWD will meet better understanding amongst their peers, and the general knowledge about dementia is enhanced. This leads to a more dementia friendly society and reduce the overall stigma.

Note: The film (duration 18 min.) with English subtitles and the educational tools will be presented.

Film: https://vimeo.com/746767067



### **Evaluation of a Dementia Awareness Game for Health Professions Students**

**Dr Gillian Carter**, Prof Christine Brown Wilson, Ms Stephanie Craig, Dr Sonya Clarke, Dr Patrick Stark, Dr Gary Mitchell

Queen's University Belfast, Belfast, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Background:** It is possible to live well with dementia and many people with dementia are living active lives with support of families, friends and communities. Nonetheless, research shows they often feel that the public, their carers and healthcare professionals do not fully realise their capabilities, instead focusing on their deficits. Healthcare professionals assume a vital role of support, and serious digital games are becoming a credible delivery method to educate/train individuals in the health sectors to challenge perceptions. A digital game to improve public knowledge and understanding about dementia (www.dementiagame.com) was co-designed with people living with dementia and was tested with health professions students to establish if it improved attitudes towards dementia.

Aim: To evaluate the impact of the dementia game on attitudes of health professions students

**Methods:** The Dementia Game was evaluated using a pretest-posttest design. Participants were healthcare professions students recruited via social media in one UK university and completed the Approaches to Dementia Questionnaire (ADQ) before and after playing the game.

**Results:** Health profession students (n=461) completed both pre and post-test questionnaires. The total ADQ score showed a significant improvement in positive attitudes (p<0.001), and both subscales of Hope and Recognition of Personhood also saw significant improvements (p<0.001).

**Conclusion:** There was a more positive view of the abilities and capabilities of people with dementia. They were also more likely to be recognised as unique individuals with the same values as anyone else. The benefit of using a serious digital game to improve attitudes of dementia was demonstrated.



### Pre-/Post-Test analysis of a dementia awareness game for Northern Ireland undergraduate nursing students.

**Miss Stephanie Craig**, Dr Patrick Stark, Prof Christine Brown Wilson, Dr Gillian Carter, Dr Sonya Clarke, Dr Gary Mitchell

Queen's University Belfast, Belfast, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Introduction:** Although it is possible to live well with dementia and many individuals with dementia lead active lives with the help of family, friends, and communities, the general impression of dementia is frequently negative. Dementia is a global health issue. Despite this, little research has been done on the effects of innovative dementia education strategies among undergraduate nursing students. The aim of this study was therefore to assess if this serious digital game, originally intended for the public, could increase knowledge about dementia in first-year nursing students.

**Methods:** The intervention was a digital serious game called "The Dementia Game", which was available to students throughout February 2021, to a convenience sample of first-year undergraduate nursing students (n = 560) completing a BSc Honours Nursing Degree programme in one university in Northern Ireland. The game was evaluated using a pre test-post test design. The questionnaire comprised of a 30- item true- false Alzheimer's Disease Knowledge Scale (ADKS), which covers risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving and treatment and management. Data were analysed using paired t-tests and descriptive statistics.

**Results:** Overall dementia knowledge increased significantly after playing the game. Pre-test to post-test increases were observed across a range of seven categories of dementia knowledge (life impact, risk factors, symptoms, treatment, assessment, caregiving and trajectory), with particularly large increases in knowledge of trajectory and risk factors, as shown using paired t-tests. All pre-test to post-test comparisons were significant at the p < 0.001 level.

**Conclusion:** A short serious digital game on dementia improved first-year student's knowledge about dementia. Undergraduate students also expressed that this approach to dementia education was effective in improving their knowledge about the disease.



### Attitudes and perceptions of the Spanish population about Alzheimer's: a public opinion survey.

Dr Nina Gramunt-Fombuena, Mr Marc Prat, Mrs Eva Nebot

Pasqual Maragall Foundation, Barcelona, Spain

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Alzheimer's, as the main cause of dementia, poses an enormous health, economic and social impact. It's essential to promote public debate and social awareness along with the capital importance of scientific research to find effective solutions. The Pasqual Maragall Foundation carried out a public survey to know the opinion of the Spanish population with a triple objective: 1) providing a comprehensive analysis of perceptions, knowledge and attitudes in relation to Alzheimer's, and its investigation; 2) identifying areas of disinformation to propose actions aimed at improving the level of general knowledge; 3) providing this data to associations and other institutions involved in addressing it.

This work includes 2,395 responded questionnaires in a representative Spanish sample (see the attached table for technical data). Topics addressed include (but not limited to): level of knowledge, proximity and concern about Alzheimer's, attitudes toward risk determination or early diagnosis, and opinions on research and willingness to participate in scientific studies.

These are some of the highlighted results are: the Spanish population has information about the basic aspects of Alzheimer's although with gaps on relevant issues; Alzheimer's is the second health condition that mainly concern the Spaniards and is regarded the main health condition aged persons face; two out of three Spaniards know someone diagnosed with Alzheimer's; seven out of ten believe that people feel uncomfortable talking about Alzheimer's; there's a wide predisposition to know the personal risk to be diagnosed with Alzheimer's; more than half of the population would take a test that allowed them to know if they're in an early phase of the condition; research in treatments and early detection should be particularly prioritized. The population is highly confident that a cure will be find, despite considering that the necessary resources are not allocated.

Technical	data

Population: general; men and women between 18 and 75 years old

Main sample: 1,000 questionnaires at the national level distributed in a representative way.

Regional sample: 1,395 questionnaires representatively distributed by regions.

Regional sample: 1,395 questionnaires representatively distributed by regions. Maximum error: ±2%; p and q values 50/50 and confidence interval of 95,5%

Field work: from April 24th to May 1st of 2023

Method: questionnaires filled from any device using Ipsos' (specialized agency) own online

system.

Median duration to answer the questionnaire: 8 minutes.

		Profile	of th	ne respo	ondents					
Gender	Men				Women					
	49%				52%					
Age (in years)	<b>18-24</b> 9%	25-34 14%	73.50		<b>45-54</b> 20%		55-65 17%		66-75 24%	
Education	Higher degree studies <sup>1</sup>	Medium grade studies	High school		Professional training studies		Secondary studies		Primary studies	
Employment situation	32% Full time	18% House chores	_	etired	17% Unemployed		10% Studying		5% Part time	
	51%	4%	22%		8%		6%		10%	
Social class	Lower/y			Middle 46%			Upper/middle-upper 40%			
Regional distribution <sup>2</sup>	Andalucía 18%	Aragó 3%	n Asturias		10000000	Canarias 5%		C	antabria 1%	
	Castilla y Leó	Manch		a		, i			munidad elenciana	
	5% Extremadura	4% a Galici	a	16% Islas Baleares		0,1% Madrid, Comunidad de			11% Melilla	
	2% 6%		3%		3%	14%		0,2%		
	Murcia, <u>Región</u> de	Navarra			Vasco Ric		ja, La			
	3%	1%		5%			1%			

<sup>1.</sup> University or higher technical degree 2. Spain is divided into 17 autonomous communities and 2 autonomous cities (Ceuta and Melilla), each with its own executive, legislative and judicial powers, and characteristic traits.



#### British adolescent's experience of dementia

Mrs Esra Hassan<sup>1</sup>, Dr Ben Hicks<sup>1</sup>, Prof Naji Tabet<sup>1</sup>, Dr Nicolas Farina<sup>2</sup>

<sup>1</sup>Brighton and Sussex Medical School, Brighton, United Kingdom. <sup>2</sup>university of plymouth, plymouth, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aims:** With a globally ageing population, and a rise in intergenerational households, there will be a greater number of people likely to be affected by dementia. Adolescents represent an under-researched group that may already have experience of dementia. In this study, we aimed to capture the level of contact adolescents have with dementia and the quality of this contact in different demographic groups.

**Methods:** This is a cross-sectional, survey study. 1371 adolescents aged 11-18 years from nine secondary schools across six regions of England took part in the study. Descriptive statistics, cross-tabulations, and logistic regressions were employed to explore the association between demographic factors and adolescent's experience of dementia and adolescent's level of contact with dementia.

**Results:** Over 64% of adolescents have come across people living with dementia, with over a quarter (27%) of adolescents stating they have looked after someone living with dementia. Females, regions with a higher level of deprivation, and non-white ethnic groups had more experience looking after someone with dementia. Adolescents reported having more indirect contact with dementia than direct contact (74% have seen dementia in TV or movie).

**Conclusion:** The findings demonstrate that the experience of dementia differs across different demographic contexts. Stakeholders should work closely with different communities and schools to support and meet the specific needs of adolescents and their families when delivering dementia awareness initiatives, taking into consideration the nuances of cultural and region-specific resources in the community.



### Dementia friends challenge: An initiative to create awareness about dementia in Mexico

#### Ms Cintia Penelope Sanchez Hernandez

Lucidity Day Care Center, Mexico, Mexico

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

The Dementia Friends Challenge Program (DFC) began in 2020 during the COVID-19 pandemic. It began as a movement to help people with and without dementia to perform virtual activities to prevent the progression of the disease during confinement; to raise awareness among people, and remove the stigma.

Together with the Mexican Alzheimer's Federation (FEDMA) and Dementia Friends Mexico (DFM), decided to carry out different virtual activities for a week (e.g.; yoga, bicycle, cupcakes etc. for dementia). The classes were recorded and uploaded (music and cupcakes). The schedules were provided so that people could join via different digital platforms. For the remaining activities photos performing the activity were uploaded to Facebook.



The first year we reached 8, 152 people. Due to the high impact, it was decided to do it yearly and the activities were modified adding Dementia Friends information sessions or sharing information on different Mexican dishes, wine or beer tasting.

Currently the activities are performed personally and virtually. Since 2020, there is also a swimming race in which 16 teams conformed by 4 swimmers participate, the challenge consists of swimming nonstop for an hour. The winner will be the team who manages to swim more kilometers in one hour; swimming up to 14 km per team in one hourln 2023, we reached 8,984 people; 76.10% were women. The most involved cities were Mexico City, Guadalajara and Mérida. The 3 countries that interacted the most were United States, Brazil and Peru; 60 Dementia Friends informative sessions were shared, reaching 10,000 Dementia Friends in Mexico.

The challenge has reached more than 30,000 people in 4 years of its implementation, changing the way of thinking about this disease. Giving the opportunity to people with cognitive impairment to perform the activities, allowing inclusion and making friendly communities for dementia.



### Awareness Raising Interventions in Schools: Education on aging and brain health for teachers – ARISE

**Dr Marcia Regina Cominetti**<sup>1</sup>, Dr Lea da Silva Veras<sup>1</sup>, Miss Leticia Fernanda Palma<sup>1</sup>, Miss Lais Rebecchi<sup>1</sup>, Miss Karen Leticia Pulgatti<sup>1</sup>, Miss Laura Soares Zuccolotti<sup>1</sup>, Dr Elaine Mateus<sup>2</sup>, Dr Robert Whelan<sup>3</sup>

<sup>1</sup>Federal University of Sao Carlos, Sao Carlos, Brazil. <sup>2</sup>Universidade Estadual de Londrina, Londrina, Brazil. <sup>3</sup>Trinity College Dublin, Dublin, Ireland

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aims:** This study aims to test the feasibility of a structured course on brain health, aging, and dementia for teachers in the late years of fundamental schools. We intend to enable teachers to effectively incorporate this content into their classes and create and share online educational materials related to aging, brain health, and dementia.

**Methods:** The program consisted of 5 modules with 30 hours of online synchronous and asynchronous activities and engaged 20 teachers from 2 public schools in a medium city in southeast Brazil. Pre- and post-intervention questionnaires were applied to understand the teachers' knowledge about dementia, brain health, and perceptions of aging. The instruments used were "Dementia Knowledge Assessment Tool Version Two", the "Ageing Perceptions Questionnaire", and "Knowledge about Dementia, Attitudes, and Behavior Towards People Living with Dementia". The project was approved by the Ethics Committee of the Federal University of São Carlos (CAAE: 58365722.2.0000.5504).

**Results:** The modules offered were (1) Introduction, (2) Understanding the Brain, (3) Aging and Cognitive Decline, (4) Dementia, and (5) Activities to Promote Brain Health. The course was offered during 5 consecutive weeks of the collective pedagogical working hours in the schools to increase attendance. Pre- and post-intervention assessments revealed a statistically significant improvement in teachers' knowledge about dementia, brain health, aging, and perceptions of aging and in reducing dementia-associated stigma. The subsequent phase in the course evaluation process will delve into the impact and efficacy of the instructional interventions suggested by the educators when implemented with the students.

**Conclusions:** The course's feasibility was confirmed by its 30-hour duration, and the online format did not hinder participation, with 85% of enrolled teachers completing all five modules, demonstrating high engagement and dedication. Having achieved promising results, we plan to expand and further develop the program in other schools.



#### Greater Awareness of Modifiable Risk Factors to Establish Links Between Neurological Conditions in Association with our Environment, Lifestyle and the Effects on Hormones Genes and Neuro Transmitters - Using Al

Mr David Savage Gallacher Ross

None, Glasgow, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

There are many forms of neurological conditions and many reasons for these. Consequently we have not discovered a cure nor are we close. Academics, scientist and students, the world over are investigating, researching and producing papers and theories into the reason for all of these individual conditions. So far, we understand some of the biomedical reasons, and that having hereditary faulty genes can, but not always be the reason for the onset of the condition.(except in Huntington's)

We understand some of the effects of genes, proteins and cell malfunction or deterioration, but in almost all cases, currently, we have not linked the many modifiable risk factors where gene methylation results.

Many journals and papers indicate the same aspects/symptoms/risk factors appearing in the majority of them, then perhaps the same factors or a combination of these factors are responsible. If we can establish the links between selected groups of neurological conditions, having the same symptoms, then research can be targeted in these areas, covering more than one condition and concentrating efforts in finding what other factors may be potential triggers. This would speed up our understanding/awareness and potentially lead to medical interventions to control and or prevent the onset of these conditions.

It has been established that many modifiable risk factors are responsible to a lesser or greater degree, the key is to determine which ones are having the most effect on things like gene methylation. To do this will take time and resources therefore, perhaps by utilizing AI we will be able to collect, collate and establish where the risks are greatest. In conjunction with our biomedical knowledge determine where to concentrate efforts in public awareness to reduce or eliminate risk factors and delay or prevent the onset. Hopefully leading to a cure.



### Shared emotions and social visibility – qualitative evaluation of the dementia awareness campaign Razem przed siebie

**Mrs Maria Błaszkiewicz**<sup>1</sup>, Dr Dorota Szcześniak<sup>1</sup>, Dr Marta Ciułkowicz<sup>1</sup>, Prof Henry Brodaty<sup>2</sup>, Prof Joanna Rymaszewska<sup>3</sup>

<sup>1</sup>Wrocław Medical University, Wrocław, Poland. <sup>2</sup>, University of New South Wales, Sydney, Australia. <sup>3</sup>Wrocław University of Science and Technology, Wrocław, Poland

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

The need for dementia awareness campaigns has been repeatedly emphasized in research and discourse in Poland. The response to this demand was the Razem przed siebie (ang. Forward with Dementia) campaign, created as part of the international project Cognisance, conducted in Lower Silesia between September 2021 and April 2022. The aim of the current research is to investigate the reception of the campaign's activities and resources among its main target groups: people with dementia and care partners.

Semi-structured interviews with people with dementia (n=14) and care partners (n=9) were conducted after end of the campaign. A qualitative thematic analysis was used as the analytical approach.

Four overarching themes were identified across the groups: (1) Emotional charge; (2) Channels of communication; (3) Key messages, (4) Importance of the initiative. Live events were the most appreciated medium. Positive emotional perception for people with dementia were often more important than the substantive content. Overtone of campaign's events also impacted care partners, especially if it meant quality time spent together with a person with dementia. However, care partners also underlined time constraints when participating in the campaign. The most important key messages for the target groups were: hope for positive life after the diagnosis, the feeling of not being alone in the condition, motivation to maintain active life. Low public awareness, little knowledge about dementia and lack of large-scale initiatives in the field of dementia were listed as arguments for the importance of Razem przed siebie campaign.

The overall experiences of the recipients with the Razem przed siebie campaign were very positive. The results underline a huge demand for social initiatives related to dementia in Poland and indicate its great appreciation by people with dementia and care partners. Presented evidences may guide the development of future, well-tailored dementia awareness campaigns.



### Dementia awareness campaign in the Indonesian migrant communities.

Mrs Manik Kharismayekti, Miss Oriana M. Rofifah, Ms Tania M. Setiadi, Mrs Amalia Fonk-Utomo Stichting Alzheimer Indonesia Nederland, Groningen, Netherlands

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Background:** Dementia in migrants poses a complex challenge for healthcare and society. This challenge is also perceived by Indonesian migrants abroad. Language barriers, cultural differences, and health perspectives can affect awareness and management of dementia. An awareness campaign accessible to Indonesian communities abroad is crucial. Alzheimer Indonesia Netherlands (ALZI Ned), supported by Alzheimer Indonesia Germany (ALZI Germany) and Ruanita Germany (NGO for social culture) collaborated on a sustainable awareness campaign through social media.

Aim: Raising awareness of dementia in Indonesian migrant communities through social media.

**Activities:** Since April 2023 ALZI Ned involved several Indonesian diaspora in the Netherlands to share their real experiences, struggles, and needs in caring for dementia people, and their involvement in dementia awareness. These stories were recorded narratively on video in their home and were used as raw material for many future series. In July 2023, we expanded our reach to include several stories from the Indonesian diaspora around the world by collaborating with ALZI Germany and Ruanita.

The first video was launched on Indonesian Elderly Day, 29 May, and subsequent materials have been posted monthly via social media. Especially between 18 and 24 September, which coincided with World Alzheimer's Month, we aired awareness content every day.

**Result:** There were many sources involved in this campaign, including 6 informal caregivers, 2 healthcare professionals, 2 ALZI overseas volunteers, and Indonesian government officials in Germany. By this time, our social media content has been viewed by 540 people (YouTube) and 2040 people (Instagram) people. There was good cooperation between ALZI Ned, ALZI Germany, and Ruanita.

**Conclusion:** A social media campaign is seen as one sustainable way to improve dementia awareness in Indonesian migrant communities. Obtaining information from several points of view can enrich people's views regarding dementia management. This activity can strengthen networks between Indonesian organizations overseas.



### Use of My Life Passports as a way to increase dementia awareness in hospitals

**Mr Jakub Tytus Majchrzak**<sup>1</sup>, Ms Mahtab Afzali<sup>1</sup>, Mr Parham Shojaie<sup>1</sup>, Dr Fouad Siddiqui<sup>2</sup>

<sup>1</sup>Aston University, Birmingham, United Kingdom. <sup>2</sup>Moseley Hall Hospital, Birmingham, United Kingdom

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aims:** Dementia patients occupy more than 25% of beds in the UK hospitals, often facing communication challenges in their care interactions. This can subsequently be an obstacle to delivering good quality of care.

My Life Passports (MLPs) are booklets that contain patient's preferences, likes, dislikes, cultural Background:, significant memories, people and places. The Alzheimer's society recommends that every patient admitted with a formal diagnosis of dementia should have an MLP. It helps to promote dementia awareness, inclusion as well as equality and battle stigma and prejudice. The absence of MLPs among some dementia-diagnosed patients at a community hospital in the UK prompted our investigation.

**Method:** We reviewed three geriatric wards within a small community rehabilitation hospital, encompassing 65 patients, seven of whom had dementia diagnoses. We sensitively engaged patients in discussions about MLPs and subsequently contacted their next of kin (NOK) via telephone to delve deeper into the issue. Upon confirming dementia diagnoses, we obtained verbal consent from the patient/NOK for survey participation and the use of their responses for audit purposes.

**Result:** The results showed that the adoption rate of MLPs was 28.6% (2 out of 7 patients), whereas the ideal rate would be 100%. Further evaluation showed that out of the five patients who did not have an MLP, four have never been informed about MLPs and one patient lost it in a prior hospital stay.

**Conclusion:** Due to a small sample size, it is reasonable to treat the results of this audit with caution. However, it suggests that there is a need for improvement in the completion rate in the studied hospital. No assumptions can be made about other NHS trusts, but it would be useful to conduct a similar study on a larger scale to identify a possible issue that can be addressed.



### Dementia Friends Mexico: Sociodemographic characteristics of the participants

**Dr Sara Torres-Castro**<sup>1</sup>, Dr Ruben Rabaneda-Bueno<sup>2,3</sup>, Dr Rosa Estela García-Chanes<sup>1</sup>, Dr Mariana López-Ortega<sup>1</sup>, Ms Rosa Farres Gonzalez-Saravia<sup>4</sup>

<sup>1</sup>National Institute of Geriatrics, Mexico City, Mexico. <sup>2</sup>IMSS, Epidemiological and Health Services Research Unit, Mexico City, Mexico. <sup>3</sup>Biology Centre of the Czech Academy of Sciences Institute of Hydrobiology, Ceske Budejovice, Czech Republic. <sup>4</sup>Federación Mexicana de Alzheimer, Mexico City, Mexico

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aim:** To study the sociodemographic characteristics of participants in Dementia Friends information sessions in Mexico.

**Method:** The information about the participants was obtained from the electronic records of the Google form implemented by the initiative since July 2020 to know the profile of the participants and provide them with their certificates that accredit them as Dementia Friends. For the purposes of this secondary analysis, the following sociodemographic variables were included: Age, gender, occupation, and geographic location in Mexico. Data were collected from July 2020 to September 2023.

**Results:** Of the 5242 participants, the average age was 33 years, most were women (75.7%), and the most common occupations were: Physicians (19.2%), medical students (12.5%), health promoters (12.1%), nurses (9.1%), psychologists (6.4%), gerontologists (5.8%), social workers (4.4%), caregivers (2.7%), physiotherapists (2.7%), and other health professionals. Participants were distributed throughout the country, with Mexico City (25%), and the State of Mexico (18.1%) having the highest participation in the centre, Yucatán in the south (6.2%) and Tamaulipas in the north (4.9%).

**Conclusions:** The Dementia Friends initiative is a programme that promotes the participation of the entire population. However, in Mexico, greater participation was observed among health professionals, especially those working or studying in elderly care.



### Promoters' experience on the Dementia Friends Global Iniciative in México: Participatory Action Research approach

Dr Sara Torres-Castro, Dr Nancy Lysvet Flores-Castillo

National Institute of Geriatrics, Mexico City, Mexico

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aim:** To explore the experiences of Dementia Friend's promoters in Mexico with a focus on Participatory-Action-Research (PAR).

**Methods.** In-depth interviews with people who have obtained their certification as Dementia Friend's promoters, from January 2019 to December 2020. 10 active promoters and 10 non-active promoters were invited to participate in the first half of 2022. Zoom interviews were scheduled for 60 to 90 minutes, and Atlas Ti software was used to process the information gained.

**Results.** Eight active promoters from the southern and central states of Mexico participated. They were coded at two levels: a) Dementia Friends Initiative elements and b) personal experiences as promotors. On the Dementia Friend's Initiative, they expressed concern over some barriers in logistics, in teaching materials, and the on-line modality. On the positive of being a promoter, the experience of being promoters stands out with professional activity and find pedagogical and communication resources to explain the dementia, they recognize their own prejudices and the need to be an initiative that generates changes that positively impact the health of people living with dementia. A was achieved meeting with state representatives for feedback and changes in the short-term process, with new goals to go to another level of action.

**Conclusion.** PAR is a methodology that contributes to improving the initiative in a constant process observation, learning and improvement. And this first approach has generated self-reflection and concern to transform the participation of promoters into new actions.



Knowledge, attitudes and perceptions of dementia and dementia care by health care professionals participating in a pilot study implementing an integrated evaluation for older adults in primary care settings.

**Dr Mariana Lopez-Ortega**, Dr Luis Miguel Francisco Gutierrez-Robledo, Dr Nancy Lysvet Flores-Carrilo National Institute of Geriatrics, Mexico City, Mexico

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aim:** To investigate the knowledge, perceptions, and attitudes towards dementia in health care practitioners (HCP) participating in a pilot project implementing an integrated care evaluation for adults 60 years including functional ability, early detection of cognitive impairment iand blood based biomarkers in primary care settings. In addition, to identify perceived opportunities and challenges by health care professionals of its implementation.

**Method:** The pilot study included four primary health care sites and 16 health care professionals who completed the GP Attitude and Confidence scale for Dementia (GPACS-D) and the Bernstein UCSF surveys at the start and end stages of the project, followed by semi-structured interviews.

**Results:** Health care professionals were 37.5% physicians, 37.5% nurses, and 25% social workers, who had been in practice around 20 years, 93% are women. Overall, they report it is important to detect dementia early, benefiting the person and their family members. However, 38% are neutral or do not feel confident in their ability to diagnose dementia. They also report significant barriers to achieving proper evaluation and management of people living with dementia, being insufficient time with patients, not being familiar with diagnostic criteria and lack of clarity about appropriate referral and treatment the most significant reported by at least 50% professionals.

**Conclusions:** To achieve health system preparedness that integrates innovative strategies for the timely detection of cognitive impairment and dementia in Mexico, primary care professionals need to be provided with optimal knowledge (training) and tools (diagnose, manage, and treat). This will increase their confidence and preparedness for optimal dementia care. In addition, proper referral channels for dementia diagnosis or discarding other conditions that cause cognitive impairment should be established in order to obtain optimal screening, diagnosis and management.



### P8-020

# Mexican Alzheimer's Federation take action for the elimination of stigma

Ms Rosa Ma. Farres González Saravia<sup>1</sup>, Dr Sara Torres-Castro<sup>2</sup>

<sup>1</sup>Mexican Federations of Alzheimer's, Mexico City, Mexico. <sup>2</sup>National Institute of Geriatrics, Mexico City, Mexico

### **Topic**

Dementia awareness: Attitudes, awareness and stigma

### Abstract

**Aim:** To understand the experience of the Mexican Alzheimer's Federation (FEDMA) when incorporating the Dementia Friends Movement.

In 2018, the Mexican Federations of Alzheimer's signed a partner agreement with the Alzheimer Society to coordinate a programme of Dementia Friends in Mexico. In the first semester of 2019 it summoned the Alzheimer associations to the first Promotor Training Course, with the intention to later disseminate it throughout the country. Six representatives of the 22 associations assisted. In the second semester another training was held during the FEDMA Conference in the North of Mexico, with the participation of five additional associations.

**Result.** The implementation process included: a translation of the manual, the creation of a logo and image for the initiative, Induction Training for Promotors Course design, and training of the first group of promotors. To date five different associations from the states of Aguascalientes, Ciudad de México, Estado de México, Morelos, and Yucatan have been working very hard since the beginning, offering Dementia Friends Informative Sessions as a part of their functions in fostering the training to new promotors. Additionally, associations in other states are preparing to achieve their recognition as Dementia Friends.

**Conclusion:** Civil associations and NGOs are not only a formal support and network for families and people with dementia, but also agents of social change in terms of stigma.



## P8-021

# Attitudes and opinions on pre-symptomatic screening for Alzheimer's Dementia in five European countries: a comparison of family and non-family members

**Mrs Marina Makri**<sup>1,2</sup>, Mrs Ioanna Antigoni Angelidou<sup>3</sup>, Prof Konrad Beyreuther<sup>3</sup>, Prof Mercè Boada<sup>4</sup>, Dr Akylina Despoti<sup>5</sup>, Prof Sebastiaan Engelborghs<sup>6</sup>, Mrs Andrea Miguel<sup>4</sup>, Mrs Isabel Rodríguez<sup>4</sup>, Dr Hannah Stocker<sup>3</sup>, Mrs Joke Temmerman<sup>6</sup>, Prof Magdalini Tsolaki<sup>1</sup>, Prof Görsev Yener<sup>7</sup>, Dr Deniz Yerlikaya<sup>7</sup>, Dr Birgit Teichmann<sup>3</sup>

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### **Topic**

Dementia awareness: Attitudes, awareness and stigma

### **Abstract**

**Aims:** Alzheimer's disease (AD) screening could play an important role in individuals with or without a family history. Globally, the need for screening is growing, it is essential to consider possible cross-cultural differences in attitudes toward pre-symptomatic screening to tailor healthcare services to the needs of each country. This study aims to investigate the attitudes of family and non-family members of people with AD toward pre-symptomatic screening and also explore possible differences in attitudes across five European countries (Belgium, Germany, Greece, Spain, Turkey) using translated versions of the "Perceptions regarding pRE-symptomatic Alzheimer's Disease Screening" questionnaire (PRE-ADS).

**Methods:** The multicultural sample (N = 650) was recruited from samples that were previously used in validation studies of the translated PRE-ADS versions. The subscale "Acceptability of Screening", consisting of five PRE-ADS focuses on a person's willingness to proceed with screening, was developed. Confirmatory factor analysis (CFA) and internal consistency were determined to investigate the psychometric properties of the scales. Group comparisons were conducted using the PRE-ADS and the "Acceptability of Screening" mean scores to look at differences in attitudes about pre-symptomatic AD screening regarding family history and place of origin.

**Results:** The PRE-ADS ( $\alpha$  = 0.76) and its subscale ( $\alpha$  = 0.90) had good internal consistency. 56.9% of the total sample expressed a positive intention for pre-symptomatic AD screening. T-tests showed significantly higher mean scores of participants with an affected family member. An international comparison revealed differences in the "Acceptability of Screening" mean score across the five European countries.

**Conclusion:** The PRE-ADS and its subscale are reliable instruments for evaluating pre-symptomatic AD screening attitudes. Differences in how people perceive screening appear to be related to cultural and familial factors. Larger sample sizes and further study are required to investigate underlying relationships.



### P9-001

# Nurturing a Community of Practice to Optimise Nature Connection for People Living with Dementia: A Journey of Development

Dr Joanna Sun<sup>1,2</sup>, Dr Pauline Marsh<sup>1,2</sup>, **Dr Cassandra Thomson**<sup>1,2</sup>, Dr Hoang Nguyen<sup>1,2</sup>

<sup>1</sup>Wicking Dementia Research and Education Centre, Hobart, Australia. <sup>2</sup>University of Tasmania, Hobart, Australia

### **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

### **Abstract**

Nature connectedness has been demonstrated to improve our physical, mental, social and emotional wellbeing. However, due to the challenges of cognitive disruptions, enabling a connection between people living with dementia and the natural environment can require a multifaceted, cooperative endeavour. Support may come from dementia advocates, health and social care professionals, outdoor health professionals, caregivers, researchers, nature-based organisations and community leaders. The Venture Out Community of Practice (VOCoP) aims to foster bonds between these enabling stakeholders and build awareness, inclusiveness, and the capability and capacity of nature-based community services to support people living with dementia and their care partners. The VOCoP's overarching mission is to drive innovation, research, and practical strategies that improve the overall well-being of individuals with dementia through a strengthened connection to nature. This presentation discusses learnings from the journey of establishing the VOCoP. The development and implementation processes included the identification of key stakeholders, setting clear objectives, establishing collaborative platforms, and fostering an environment conducive to knowledge sharing and collaborative learning and action. Various qualitative and quantitative research methods were adopted to assess the effectiveness of the CoP, including surveys, interviews, and content analysis. The VOCoP currently organises meetings and produces materials that are widely accessible, shared, and co-designed by all stakeholders. These stakeholders serve as catalysts, accelerating progress and enhancing the quality of research and practical initiatives aimed at connecting people living with dementia to nature-based community services. The creation of a CoP for professionals and organisations delivering nature-based services is a progressive step toward significantly improving the care landscape and quality of life for people living with dementia. This presentation invites further discussion on the potential of CoPs in enhancing the delivery of naturebased enablement services and fostering collaborative environments for professionals involved in community-based support for people living with dementia.



### P9-002

## Towards interdisciplinary team in developing a training module for Alzheimers and Social Work

Prof Sahar Suleiman Almakhamreh<sup>1</sup>, Dr Amal Saif<sup>2,3</sup>, Mr Hamza Nouri<sup>4</sup>, Dr Maysson Fakhoury<sup>5</sup>

<sup>1</sup>German Jordanain University, Amman, Jordan. <sup>2</sup>Yemen Foundation against ALZ Dementia (YFAAD), Sana, Yemen. <sup>3</sup>Yemen Foundation against ALZ Dementia (YFAAD), sana, Yemen. <sup>4</sup>Al Oun For Alzheimer's Patient Care Association (AACA), Amman, Jordan. <sup>5</sup>Albalqa Applied University, Amman, Jordan

### **Topic**

Dementia awareness: Community partnerships / Public-Private-People partnerships

### **Abstract**

This paper explores the collaborative efforts between social work academics and professionals from Jordan and Yemen in designing a comprehensive training module for Alzheimer's patients and their families in Jordan. The primary objective is to bridge social work theories, approaches, and practices with dementia care, emphasizing policy advocacy and its impact on individuals, families, and societies.

The training module was delivered to 22 MA social work migration and refugees students over seven consecutive days, with a concentrated focus three hours peer day. The methodology involved focus group discussions and field notes collected from students after their field placements. Additionally, a follow-up focus group was conducted one year later with the same students who underwent the training.

Results indicate a significant increase in students' awareness of dementia, recognizing the importance of social care and family support alongside medical care. The study also underscores the pressing need to develop community services to address the escalating needs of individuals living with dementia and their families. Furthermore, ethical implications for social workers operating in the health domain, such as considerations for dignity and worth, are highlighted.

This collaborative initiative provides valuable insights into the development of interdisciplinary training modules, emphasizing the crucial role of social work in enhancing the holistic care and support for individuals affected by Alzheimer's disease.



### The story of impaired seniors and dementia

### **Mrs Marianne Wilfling**

Lebensgross, Graz, Austria

### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

### **Abstract**

We are an organization based in Styria, which has decided to support impaired people in all situations of life. For the fact that in the work with impaired people, on the one hand, there is medical support and, on the other hand, now the generation after the Hitler regime is approaching the senior age, we also have in our day center for impaired senior women, a focus on dementia

As a very busy professional, I would like to draw a bow between dementia in the conventional senior age and how we live our work and meet our participants with dementia.

Based on our day center, working with impaired seniors is often already very challenging, but if the "assumption" or diagnosis of dementia is added, the challenges increase massively.

We accompany 30 participants, of which there are 5 diagnosed forms of dementia, our dark figure is much higher. That's why I decided to further educate myself to become a dementia manager. In the course of this I offer training for colleagues and work intensively with the impaired people and dementia. In my daily work it is very difficult to make diagnoses, because there are hardly enough suitable doctors, etc. who want to deal with my clientele. The combination of Down syndrome and dementia is an very exciting work and an very emotional challenge, because of the rapid progression.

With my abstract I want to communicate that impaired people also experience dementia and thus also show this picture to the population



## Dementia-Friendly Communities (DFCs) to Improve the Quality of Life for People with Dementia: A Realist Review of the Literature", do you need the full abstract for this?

Miss Stephanie Craig, Dr Peter O'Halloran, Dr Gary Mitchell, Dr Patrick Stark, Prof Christine Brown Wilson

Queen's University Belfast, Belfast, United Kingdom

### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

### **Abstract**

**Background:** The main elements of a DFC are related to people; communities; organisations and partnerships. There are over 200 organisations recognised as dementia-friendly in Northern Ireland (NI). This realist evaluation was to understand how DFCs work for people living with dementia, how positive outcomes are achieved, for whom and in what contexts do DFCs work best.

**Methods:** The underpinning theoretical lens that was used in this study is realist evaluation. This is a theory-driven methodology that supports researchers in evaluating social programmes, such as DFCs. Realist evaluation, as opposed to a traditional cause-effect, non-contextual style of research, suits the complex social intervention of DFCs as an alternate lens to traditional empirical evaluation techniques, as this perspective seeks to determine what works, for whom, in what circumstances and to what degree. A qualitative approach involving non-participant observation (n=10) and four focus groups involving people living with dementia and their carers and staff working in DFCs was utilised.

**Results:** The programme theory comprised 4 interconnected context- mechanism- outcome configurations: 1) a dedicated time for people living with dementia in large public shops where it is quiet and less busy; 2) increased support in public settings or businesses from employees or volunteers; 3) environmental changes that are dementia focused and promote an inclusive community; 4) generating dementia awareness and delivering educational training.

**Conclusion:** Mechanisms perceived by participants in this study provide support for an existing theory as proposed in the framework developed in a previous review in stage 1 of this study. This research provides important pieces of the explanatory jigsaw that will help us understand how DFCs work for people living with dementia, for whom and in what contexts do DFCs work best.



# Preliminary Findings of A Realist Evaluation exploring the experiences of people living with dementia in Dementia Friendly Communities (DFCs) in Northern Ireland

Miss Stephanie Craig, Dr Peter O'Halloran, Dr Gary Mitchell, Dr Patrick Stark, Prof Christine Brown Wilson

Queen's University Belfast, Belfast, United Kingdom

### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

### **Abstract**

**Background:** The main elements of a DFC are related to people; communities; organisations and partnerships. There are over 200 organisations recognised as dementia-friendly in Northern Ireland (NI). This realist evaluation was to understand how DFCs work for people living with dementia, how positive outcomes are achieved, for whom and in what contexts do DFCs work best.

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## Dementia Customers and Financial Services-Preliminary Surveys in Taiwan

Ms Pei-Hsuan Lee, Ms Yun-Ching Chen

Taiwan Alzheimer's Disease Association, Taipei, Taiwan

### **Topic**

Dementia awareness: Dementia friendliness and inclusivity

### **Abstract**

Finance is an essential part of our daily lives, and inclusive finance is an important element of a dementia friendly society. Financial Supervisory Commission R.O.C (Taiwan) stipulated "Economic Security Protection Program for People with Dementia (20201-2025)" in 2021. Subsequently, "Practical reference practices for banks to serve people with dementia or suspected dementia" and "Reference practices for the trust industry to service people with dementia or suspected dementia" were announced in 2023. In order to preliminarily understand the experience of families with dementia using financial services and the attitude of bank practitioners in serving people with dementia, Taiwan Alzheimer's Disease Association (TADA) released online questionnaires in mid-2023. The former received 123 responses, while the latter received 92 responses. The results show that the overall experience of using financial services among families with dementia is negative. More than 80% of families with dementia said they had encountered unfriendly or difficult situations when using financial services. The common situations they encounter include that people with dementia are refused service, the guardian or family member are hard to handle bank affairs on behalf of the person with dementia, people with dementia have difficulty in using digital services and ATMs, etc. On the other hand, more than 60% of bank practitioners expressed a lack of confidence in serving people with dementia. The challenges they face include identifying whether a customer may have dementia, assessing the client's current mental capacity, evaluating whether to refuse the current services, etc. Our preliminary surveys indicate that it is necessary to improve financial practitioners' awareness of dementia and their ability to support people with dementia, discuss the possibility of adjusting the service processes and design dementia friendly environment. TADA hopes to promote dementia-friendly communities by assisting financial institutions to enhance dementia awareness, understanding and coping skills.



## **Evaluation of the implementation of the Dementia Friendly in Santos/Brazil**

**Dr Emanuela Bezerra Torres Mattos**<sup>1</sup>, Ms Maryana Helen Szram<sup>2</sup>, Ms Giulia Meneghetti Rebello<sup>2</sup>, Dr Patricia Masterson-Algar<sup>3</sup>, Prof Gill Windle<sup>3</sup>, Dr Catrin Hedd Jones<sup>3</sup>, Dr Deusivânia Vieira da Silva Falcao<sup>4</sup> 
<sup>1</sup>UNIFESP, São Paulo, Brazil. <sup>2</sup>Unifesp, São Paulo, Brazil. <sup>3</sup>Bangor University, Walles, United Kingdom. 
<sup>4</sup>USP, São Paulo, Brazil

### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

### **Abstract**

**Introduction:** In developing countries like Brazil, estimates for the number of cases of people with dementia are expected to triple by 2050, reaching 150 million. International organizations have encouraged the implementation of a global action plan, and strategies and initiatives called "Dementia Friendly" have been incorporated in countries in Europe, Asia, Africa and the United States as an important social technology to minimize stigma and promote knowledge about dementia. Objective: Evaluate the implementation of the Dementia Friends sessions in Santos.

**Method:** The project has already been submitted and approved by the Santos Municipal Health Department and the Human Research Ethics Committee of the Federal University of São Paulo (UNIFESP). Qualitative exploratory research will be carried out to offer Dementia Friends sessions. Inclusion criteria: be 18 years of age or older; work and/or study at UNIFESP; be a professional in any area of the Santos Medical Specialties Outpatient Clinic (AMBESP) or users of the Social Service of Commerce (Sesc) in Santos. Registration will be done through an online form (with sociodemographic data and other data related to motivation and skills) available on the UNIFESP website. The sessions will take place from February to March 2023 in a face-to-face format, with a minimum number of 5 and a maximum of 20 participants. All meetings will be recorded and transcribed. After 1 month, all participants will receive a form by email to evaluate how much they are applying and multiplying the sessions.

**Expected Results:** It is expected that there will be a better understanding of dementia, as well as attitudes towards people with dementia and their families in the contexts in which participants circulate, in order to minimize stigma.



# Making hospitals more dementia-friendly: A multi-stakeholder approach.

Dr Sarah E Endicott, Dr Lisa Bratzke, Dr Diane Farsetta

University of Wisconsin, Madison, USA

### **Topic**

Dementia awareness: Dementia friendliness and inclusivity

### **Abstract**

People living with dementia and their care partners identify interactions with the healthcare system among their biggest challenges. Hospital settings are particularly challenging for people living with dementia, due to staff and schedule changes, unfamiliar and disorienting environments, and strange noises. Hospital staff often do not feel prepared to care for people living with dementia. Hospitals are increasingly challenged to manage the care of people living with dementia under the constraints of staffing shortages, Covid-related restrictions, and delays in discharging patients to long-term care facilities. An academic team with expertise in education, geriatrics, simulation, and community outreach previously developed dementia-friendly training materials for classroom and community use. Following that toolkit's release, the team received a request to develop training materials that specifically address the challenges that people living with dementia, their care partners, and staff face in hospital settings. Therefore, the team reconvened to design and pilot test a dementia-friendly hospital toolkit. To ensure the toolkit's relevance and usability, the team utilized a user-centered design approach that engaged multiple stakeholders over two years, including care partners of people living with dementia, hospital staff, hospital leadership, and advocates from communities disproportionately impacted by dementia. Based on the experiences of hospitals that had developed their own dementia friendly programs and aligned with the general principles of dementia friendly initiatives, training materials were designed for use by hospital staff across roles, fostering an organization-wide approach. The toolkit also includes a robust planning guide to facilitate uptake by a wide range of hospitals, that allows large academic centers to rural critical access hospitals to develop a training plan specific to their organization's needs and goals. This presentation describes our multi-stakeholder, user-centered design approach, the training and organizational materials, as well as lessons learned from implementation pilots with five partner hospitals.



# ESCAPERS Erasmus + Project: : Intergenerational learning and cultural exchange methodology through ESCAPE Rooms in care centers for Seniors

Ms Konstantina Vasiliki lakovou<sup>1,2</sup>, Ms Asimina Brouzou<sup>1</sup>

<sup>1</sup>Challedu, Athens, Greece. <sup>2</sup>Aristotle University of Thessaloniki, Thessaloniki, Greece

### **Topic**

Dementia awareness: Dementia friendliness and inclusivity

### **Abstract**

The European population is rapidly aging, with over 21.1% of the EU citizens being 65 years or older in 2022. A significant portion of seniors, especially those living alone (32% compared to 14% of the total population), face social isolation and loneliness, particularly those aged 65 and above. On the other hand, seniors living in residential care facilities are often stigmatized.

As lifespans increase, there is an urgent need to establish innovative intergenerational initiatives that actively involve both seniors and younger generations to address these social challenges.

In line with this trend, ESCAPERS Erasmus + project aims to transform residential care facilities into escape rooms, where seniors (even those living with dementia or MCI) are playing with visitors - students, refine the aforementioned methodology and expanding it in an international context.

This project's concept originated from a previous project called "Mystirio sto girokomeio" (Mystery in Nursing home), funded by the Tima Foundation (Greece), carried out by Challedu in 2019-2020. During this project, Challedu partnered with four residential care facilities for seniors and co-designed with seniors four mystery games based on their reminiscences and interests.

Among the key objectives of the project are to:

- promote intergenerational game based learning opportunities
- promote social inclusion of seniors and bring them out of isolation
- empower the digital skills of seniors
- promote the civic engagement of younger generations

Its results are

- the ESCAPERS Methodological guide
- the 5 escape games
- a guide on ESCAPERS local labs, during which the escape games will be tested

The project will last 24 months and is coordinated by CHALLEDU (Greece) and the partnership includes the The Gaiety School of Acting Ireland), Eduvita (Italy) ASOCIACIÓN FAMILIARES ALZHEIMER VALENCIA (Spain) and Odd Statue Games(Greece).



# Let's play cards! - Development of a card-based game to explore meaningfulness in the life-world of people living with dementia at home

**Dr Saskia Kuliga**<sup>1,2</sup>, Ms Anne Fahsold<sup>1,2</sup>, Mr Manuel Julius Strotmann<sup>3</sup>, Dr Daniela Templin<sup>1,2</sup>, Ms Marie Wohlan<sup>1,2</sup>, Dr Vincent Langenfeld<sup>4</sup>

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### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

### **Abstract**

**Aims:** We developed a card-based game to explore which aspects people with dementia living at home might find meaningful, when describing their life-world, and which role spatial orientation might play in their everyday life. Our underlying rationale is that a card-based game might serve as research tool to ignite narrations of what constitutes the life-world from the perspective of people with dementia.

**Methods:** Based on research literature, we deducted lifeworld-oriented umbrella terms that were sufficiently broad to capture diverse perspectives yet also sufficiently specific to enable in-depth conversations. After iterative rounds of content reduction, 22 cards – representing social network, environment, activities, and support structures – were printed on paper, as well as integrated in tablet-based digital game. Game interactions are performed as follows: In the first round of gameplay, the researcher (interviewer) presents all cards – one-by-one – to the player (person with dementia), so that the player can familiarize themselves with all cards. Second, the player can choose cards that are meaningful from their perspective, and place remaining cards either in a discarded pile or keep them nearby for later consideration. Third, the researcher places a stick figure image in the middle representing the player. The player is asked to sort all chosen cards either closer or further away, depending on how meaningful these are to them. Finally, we ask whether the resulting image represents their life-world on the particular day. The player can then swipe all cards off the play area to end the paper/digital game.

**Results/Conclusion:** Players who interacted with the card-based game experienced that they considered aspects about their life-world that they had not considered before. They felt it supported talking about lived experience and that the game was enjoyable. We discuss different images of perceived life-worlds and reflect on the game, the cards, and the interactions.





### P11-001

## Profile of dementia patients attended at neurology outdoor clinic in a tertiary care hospital of Bangladesh.

### Dr Abul Kalam M Shoab

Sylhet MAG Osmani Medical College, Moulvibazar, Bangladesh

### **Topic**

Dementia awareness: Development, growth and the role of Alzheimer and dementia associations

### **Abstract**

Health priority because it causes the devastating economic burden on families and nations. However like some other developing countries it is not known much about the demographics, characteristics, and associated conditions of dementia patients in Bangladesh.

Objective: To study profile of dementia patients from a tertiary level hospital in Sylhet, Bangladesh.

**Methods:** This observational study was conducted on patients with mild to moderate dementia attended in the outdoor clinic of Neurology Department, Sylhet MAG Osmani Medical College, Bangladesh, during the period of July 2017 to June 2018. Data were collected by face to face interview with semi structured questionnaire.

**Results:** Total number of patients was 71, mean age was 62±7.02 years, 53.5% were male, 50.7% were from rural area, and 95.7% were Muslim. Mean duration of illness was 25.20±9.25 months; the type of dementia most commonly diagnosed was Vascular Dementia (VD) 47.9% of total cases. Various risk factors (e.g. smoking, hypertension, stroke etc) were present in 64.79% cases. Baseline MMSE score before drug treatment was 14.39±2.95 after treatment at 12th week which was 19.95±3.50 (p<0.001).

**Conclusion:** This study has provided baseline information about dementia patients such as mean age, gender, sociodemograhy, type of dementia and treatment response.

### **Keywords**

Dementia; Cognitive Function,



### P11-002

## #WeLightBucharestPurple - Another brick in transforming Bucharest into a dementia-friendly community

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### **Topic**

Dementia awareness: Development, growth and the role of Alzheimer and dementia associations

### **Abstract**

A dementia-friendly community defines a locality where people living with dementia (PwD) are understood, respected, supported, and confident that they can contribute to the life of the community, while community members are aware and attentive to the needs of PwD.

During this project, we established four major objectives. The first objective is to maintain the degree of functioning and social interaction for PwD by organizing a set of Story2Remember (S2R) creative drama workshops. In parallel with the first objective, we aim to offer to the family members (FM) organizing support groups focusing on psychoeducation. We also aim to progressively increase the degree of social integration of PwD and FM by organizing 5 Alzheimer's Cafes and 3 community events. The last objective is to raise awareness about dementia among the general population and key actors in the community by organizing an awareness and fundraising campaign for long-term creative drama groups, support groups, and Alzheimer's Cafes.

To address this issue, we will offer direct services and the opportunity to participate in events that will progressively bring them out of isolation. At the level of direct services, we will organize a set of 4 weekly S2R workshops for 25 people with dementia in parallel with the organization of support groups for 25 MFs (10 beneficiaries per series). In order to increase the social support offered to PwD and FM, we will organize monthly Alzheimer's cafes for 30-40 people, to which we will invite all beneficiaries of the project as well as professionals. To increase the visibility of dementia, we will organize an awareness and fundraising campaign, which includes a communication campaign and 3 community events for 300 people. Thus, #WeLightBucharestPurple represents yet another brick in transforming Bucharest into a dementia-friendly community.



### P12-001

# Walking the talk for dementia: A unique immersive, embodied, and multi-experiential initiative

### Mr Fernando Aguzzoli-Peres

Global Brain Health Institute, Dublin, Ireland. International Longevity Center Brazil (ILC BR), Rio de Janeiro, Brazil. BrainLat, Santiago de Chile, Chile

### **Topic**

Dementia awareness: Diverse populations – inclusion, equality, cultural issues

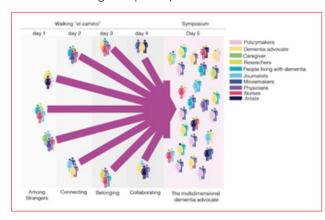
### **Abstract**

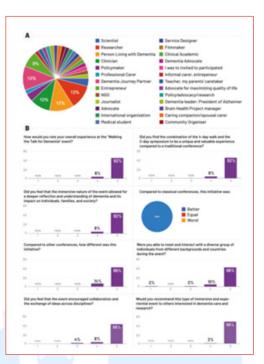
Coping with the complexity of dementia requires an integrated approach encompassing personal, health, research, and community domains. The "Walking the Talk for Dementia" is an immersive experience aimed at empowering people with dementia, enhancing dementia understanding, and inspiring collaborations for care and research. This initiative was piloted in 2023 involving 300 participants from 25

nationalities, including people living with dementia, care partners, clinicians, policymakers, researchers and advocates for a four-day, 40 km walk through the Camino de Santiago de Compostela, Spain. Participants were able to deepen connections and diversify their understanding by sharing experiences across social, geographical, cultural, and professional backgrounds. A two-day symposium after the journey facilitated integration and sharing, emphasizing transdisciplinarity and horizontal power structures, deconstructing traditional hierarchies. Participant-based case studies and surveys demonstrate immediate impacts on personal, scientific, and health domains.

Benefits of the experiential approach encompass a wide range of advantages. It provides the opportunity to foster connections and lead by example, promoting open discussions for a deeper understanding. Additionally, it plays a pivotal role in building a supportive community where individuals are encouraged to embrace vulnerability. This approach ensures equitable engagement, nurturing inclusive conversations and facilitating effective communication.

Walking the Talk for Dementia complements traditional conferences on brain health. Where traditional formats sometimes restrict people living with dementia and care partners involvement and interdisciplinary connections and collaborations, this initiative champions inclusivity, diversity, empathy, and collaborative exchange and learning. The initiative holds potential to enhance the lives of people living with dementia and their partners profoundly.







The Welsh Ambulance Service provides unscheduled and planned services, including telephone and online advice. We support many people affected by dementia as they access, use and move through our services. Co-production underpins our dementia programme, leading to innovative improvement work including the development of dementia and sensory friendly environments.

#### Miss Alison Johnstone

Welsh Ambulance Services NHS Trust, Wales, United Kingdom

### **Topic**

**Dementia awareness:** Environment and architecture for dementia

#### **Abstract**

We have worked in partnership with people affected by dementia to develop more optimal environments inside our vehicles. We receive safety reports and patient feedback on situations where our environments including vehicles, processes, and staff interactions have an impact on the experiences of people when in our care. People have told us that lighting, noises, colours, lack of communication and reassurance (particularly in an emergency) can be distressing, confusing and cause anxiety.

"We get very stressed about noises, it's an overload on our senses".

"The floor looks like it's moving, the glitter design is distracting".

This involves ongoing consultation exercises with dementia and carers groups, as well regular research and literature reviews on how we can create friendlier environments.

This feedback has led to the introduction of many improvements, including reminiscence therapy, where we use digital solutions to develop meaningful interactions with dementia patients, which can provide distraction activities and different sensory experiences, including music, games, films and more. We know that these opportunities support patients and carers on a long journey, on a long delay outside hospital or those who just require distraction due to boredom, distress, confusion or even pain.

We have changed flooring and seat colours, adding pictures and imagery to windows and blinds in the back of vehicles.

This is an exciting culture shift for us, so we are keen to test and track the outcomes of this work, to make sure it leads to positive outcomes and experiences for dementia patients.



## Beyond Borders: Dementia Villages - A Paradigm Shift in Global Dementia Care

**Dr Valentina Scarton** 

luav University, Venice, Italy

### **Topic**

**Dementia awareness:** Environment and architecture for dementia

### **Abstract**

This contribution examines the global landscape of dementia care facilities, with a particular focus on the emergence of 'dementia villages' in 2008. Motivated by the urge to create a living environment that fosters a community spirit and allows residents to be independent, the analysis examines the extraordinary challenges and prospects associated with this pioneering technique. The idea of a dementia village is not only a pragmatic solution to the demands of inclusivity and acceptance of dementia as an aspect of existence, but also a fascinating research and case study for future iterations. These villages illustrate the de-institutionalization of care in two significant ways: through their social value as familyoriented communities with shared spaces, and through a departure from traditional care structures, both in terms of architecture and urban planning, in favor of a neighborhood-centered approach. They also redefine the human experience by removing medical clothing and hospital-like environments. The presentation examines the reasons for the establishment of Dementia Villages through an analysis of the Dutch architectural context of the 1960s and 1970s, which first introduced the idea of village/ neighborhood models as part of care and inclusion. Through three main themes - urban layout, relational spaces, and the domestic environment - the study illustrates the advantages and disadvantages of this model through three exemplary projects: De Hogeweyk Dementia Village in the Netherlands, Carpe Diem Dementia Village in Norway, and Le Village Landais Alzheimer in France.



# The Architectural Dimension of the National Action Plan for Dementia –Alzheime's Disease in Greece: Current Regulatory Framework and Recommendations

**Ms Konstantina Vasiliki lakovou**, Prof Kyriaki Tsoukala, Prof Magdalini Tsolaki Aristotle University of Thessaloniki, Thessaloniki, Greece

### **Topic**

Dementia awareness: Environment and architecture for dementia

#### **Abstract**

The report by Alzheimer's Disease International (ADI) for the year 2020 recognizes architectural design as one of the means that allow people living with dementia (pwD) to live with dignity respecting at the same time their own vision of life. However, this parameter is not clearly reflected in all the already published National Dementia Plans (NDP).

The development of the Greek NDP (Greece National Action Plan for Dementia 2016-2020) recorded deficiencies in care facilities (eg residential care units and palliative care units). Therefore, action strategies were planned to address them. This included the certification and continuous evaluation of specialized residential care units to meet the needs of pwD living in them. Additionally, it encompassed the construction of 2 palliative care units, as well as the reuse and adaptation of existing buildings to meet the increasing need for beds.

The Greek NDP was reinitiated in May 2023, as a part of a holistic Action Plan for Mental Health for 2030. Among others, it contained recommendations for creating residential care units tailored to the needs of pwD and increasing the number of palliative care units.

In this study, the authors will attempt to assess the existing regulatory framework for the construction of residential care units, palliative care units, and other related facilities for pwD, considering the current bibliography on dementia-friendly design and actions proposed during the two stages of Development of the Greek NDP. The aim of our analysis is to formulate recommendations for future improvements to the Greek context and NDP-related actions.



# How do residents with dementia in long-term care facilities assess their living environment? :photo-elicitation interview

Ms Yuria Yamasaki, Prof Harue Masaki

Chiba University, Chiba, Japan

### **Topic**

**Dementia awareness:** Environment and architecture for dementia

### **Abstract**

**Aim:** Environmental assessment for long-term care facilities still lacks consideration of assessment areas from the perspective of residents with dementia. This study aimed to determine how people with dementia who reside in long-term care facilities evaluate their living environment.

**Method:** Semi-structured interviews were conducted with six residents of Japanese long-term care facilities with cognitive decline, using a photo-elicitation method. While looking at the photos of places where the participants spent time and favorite objects, the participants talked about the objects in the photos and the comfort of the place. The interview data were analyzed using the KJ method. The first author was involved in the entire analysis process and consulted with the second author at each step to ensure validity and credibility. This study was approved by the Ethics Review Board and supported by JSPS KAKENHI22KJ0474.

**Results:** Participants were five women and one man in their 80s to 90s. The length of stay ranged from 3 to 17 months, and Functional Assessment Staging of Alzheimer's Disease 4-5. Photographs ranged from 6 to 12 per participant; interviews averaged 39.7 minutes.

Participants evaluated the environment from the following perspectives: connection with family and previous experiences, connection to a cherished location, continuity of living, a well-organized living environment, a place with a sense of control, and relationships with other residents and staff.

**Conclusions:** The participants rated their environments in terms of their connection to crucial objects over the years, the continuity of their future lives, the balance between support and self-control in their current living environment, and their relationships with others. These areas suggest requirements for the care facility environment to be meaningful for the individual. To utilize these results as an indicator for environmental assessment, we need to consider how to set up an appropriate rating scale.



# Sensitising students of architecture and medicine to the perspective of people with dementia: Reflections on an interdisciplinary university course

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### **Topic**

Dementia awareness: Environment and architecture for dementia

### **Abstract**

**Aims:** The World Alzheimer Report 2020 urged educators to integrate knowledge about design for people living with dementia into the curricula of schools of architecture and design. Moreover, studies have emphasized the role of inclusive design for homes, communities and public spaces including hospitals. In this contribution, a psychologist, architectural student and an architect by profession reflect on an interdisciplinary university course for students of architecture and medicine.

**Method:** For three semesters, we ran a university course that included interdisciplinary expert lectures, hands-on design thinking tasks, and a preparation of a poster for a public museum exhibition. Also, students navigated to different destinations in a hospital in Munich, Germany, to identify areas that were challenging for spatial orientation and wayfinding. By means of both walk-throughs, perspective-taking tasks, and spatial analyses via space syntax, students reflected on wayfinding challenges they encountered, and were also invited to anticipate the perspective of a person living with dementia.

**Results:** Students critically reflected on building-, person- and task- characteristics that contributed to their own wayfinding- and orientation challenges in the hospital. However, despite expert input they had received, they faced challenges in anticipating the perspective of a person living with dementia. Nevertheless, they were inspired to further reflect on the perspectives and needs of this user group in their later profession in medicine and architecture. Based on these findings, in a subsequent iteration of the course, we asked the next group of students to redesign the existing space to specifically support people with dementia in orienting and finding their way in the particular hospital.

**Conclusions:** We critically reflect on this effort to integrate knowledge about inclusive design into the curricula of schools of architecture and design by describing potential barriers remaining and identifying opportunities and didactic methods for educators.



# Understanding the Experience of Hearing Loss for People Living with Lewy Body or Parkinson's Disease Dementias

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

**Aims:** Evidence suggests that hearing loss is common in people living with dementia. Moreover, hearing loss appears to be a possible, potentially modifiable, risk factor for incident dementia. Despite such evidence, little consideration has been given to the experience of hearing loss in dementia, specifically certain subtypes, and how the occurrence of hearing loss may influence a person's quality of life. Therefore, this study aims to further understand the experience of hearing loss specifically for people living with Dementia with Lewy Bodies and Parkinson's Disease dementia (hereafter Lewy pathology dementia).

**Methods:** A series of semi-structured interviews with people living with Lewy pathology dementia and unpaid carers of people living with Lewy pathology dementia will be conducted. The interviews will focus on the experience of hearing loss for people with Lewy pathology dementia, the pathway of accessing audiology assessment and audiology treatment, and the barriers to audiology services. The study concept and interview schedule was co-developed with people living with lewy pathology dementia and unpaid carers.

**Results:** Interviews are ongoing, due to be completed by February 2024. Therefore, these findings will be presented at ADI for the first time.

**Conclusions:** This study may have important implications for dementia care. Specifically, the interviews may provide further insight as to the unmet needs of people living with Lewy pathology dementias and hearing loss, and the potential barriers to hearing loss treatment in people with Lewy pathology dementias.



# A Review of Studies Regarding Delirium Superimposed on Dementia among Older Patients in Acute Care Hospitals

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

**Background:** Older patients admitted to the surgical setting have a high prevalence of delirium superimposed on dementia (DSD), a comorbidity of delirium and dementia. However, DSD is poorly recognized by health professionals. In addition, because symptoms of DSD are similar to those of dementia, DSD is often mistaken as a behavioral and psychological sign and symptom (BPSD). Thus, it is difficult to detect.

**Objective:** The study aim was to review the previous literature regarding DSD in older patients admitted to acute care hospitals.

**Methods:** Previous studies were searched with keywords (Delirium superimposed on dementia) AND (review) on Pubmed. Relevant research articles cited in searched articles were also examined.

**Results:** Thirty-four systematic and narrative reviews appearing after 1991 were included in the analysis. The following findings emerged from the literature: (1) the probable cause of DSD is neuronal dysfunction resulting from inflammation, hypoxia, and other stresses, though the exact pathophysiology is unknown and inconsistent with diagnostic criteria and guidelines; (2) risk factors include being a man, the severity of comorbidities, comorbid psychiatric disorders, and pain; (3) for patients with dementia and the onset of DSD, cognitive impairment and BPSD worsen, leading to increased hospital stays, mortality, readmission rates, family caregiving responsibilities, and costs; (4) since the effectiveness of non-pharmacological preventive methods has been demonstrated, early detection of DSD and appropriate action may be necessary. However, no DSD-specific detection tools are currently available; and (5) the Confusion Assessment Method (CAM) is an effective assessment tool, but tools for rapid screening have not yet been developed.

**Conclusion:** Study findings indicate the need to develop a tool to detect and diagnose DSD early and conveniently. Additionally, further research regarding effective treatment is recommended.



The literature review and 2023 update of A Clinician's BPSD Guide: Understanding and helping people experiencing changed behaviours and psychological symptoms associated with dementia, and CareForDementia: Supporting care partners to better understand and help people experiencing changed behaviours and psychological symptoms associated with dementia – mobile apps and text resources

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Centre for Healthy Brain Ageing (CHeBA) at UNSW Sydney (University of New South Wales), Sydney, Australia

### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

#### **Abstract**

**Aims:** Update the original 2012 version of *A Clinician's BPSD Guide* and *CareForDementia* (c4d) mobile apps and text in line with current evidence to provide guidance for clinicians, care home staff and community care staff who support people living with dementia who are experiencing behaviours and psychological symptoms associated with dementia (BPSD).

**Method:** We conducted a systematic search (Pubmed, Medline, Embase, PsycInfo) and literature review of studies of psychosocial and environmental and biological interventions that addressed BPSD published between 2012-2021. We rated the research quality based on predetermined criteria, then updated the existing mobile app and text information based on the current moderate to strong quality research evidence and including advice from the most recent clinical guidelines and other sources. Final versions of the updated resources were reviewed by frontline expert advisors, dementia support specialists working with people with lived experience, and through broad consultation. Funding for the update was provided by the Australian Government Department of Health and Aged Care.

**Results:** Evidence from 420 studies of psychosocial and environmental intervention and 221 studies of biological intervention were identified, reviewed, rated for quality, and effect sizes calculated where possible: 348 moderate to strong quality studies of psychosocial and environmental interventions and 178 studies of biological interventions were included in the final update.

**Conclusions:** The volume and quality of published research evidence regarding interventions to help people living with dementia who experience BPSD have increased dramatically since 2012. Ongoing update of existing evidence is necessary. The 2023 updated versions of the original *A Clinician's BPSD Guide* and *CareForDementia* (c4d) apps and text resources are now available and free for download, providing guidance for clinicians and care staff and supporting care partners in better understanding and helping people living with dementia who are experiencing changed behaviours and psychological symptoms associated with dementia.



## Performance Analysis and Improvement Measures for the Dementia Specialized Care Hospital's Incentive Program for the Treatment of Severe Behavioral and Psychological Symptoms of Dementia

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

**Background:** The Ministry of Health and Welfare designates select facilities as Dementia Specialized Care Hospitals (DSCH), focused on treating dementia patients with severe Behavioral and Psychological Symptoms of Dementia (BPSD) who can't be adequately cared for at home. Therefore, the policy objectives of DSCH are: first, early intervention with a multidisciplinary team for BPSD patients, aiming for discharge within 90 days to reduce long-term hospitalization. Second, facilitating patients' return to their communities for aging in place (AIP). To support dedicated personnel and program operation for BPSD treatment, an incentive program has been launched.

**Aims:** The pilot program's objectives are providing incentives to medical institutions for achieving these goals and evaluating the program's effectiveness.

**Method:** An analysis compared hospitalization duration, community reintegration rates, and results from the Neuropsychiatric Inventory Questionnaire (NPI-Q) and Korean Delirium Rating Scale (K-DRS) for incentive recipients before and after admission

**Conclusions:** From March 2021 to September 2022, 49 patients participated, with 9 (18.0%) receiving incentives.

**Results:** Average hospitalization for these 9 patients was 44 days; 5 (55.5%) returned to the community; NPI-Q symptom items decreased from 4.9 to 2.0 on average, and K-DRS scores decreased from 21 to 6.8 points.

The limited number of incentive recipients made it challenging to derive statistically significant results. Recommendations for phase two include expanding participating institutions, increasing incentives, and revising hospitalization duration targets.



# **Enhancing Dementia Care: Exploring the Therapeutic Impact of Fidget Blankets on BPSD at ARDSI Hyderabad Deccan Chapter**

**Ms Thashreefa Binth Muhammed Sherif**<sup>1,2</sup>, Ms Saadiya Hurzuk², Dr Najamus Saquib<sup>1,2</sup>, Dr Chandrasekhar Kammammettu<sup>1,2</sup>, Dr Mani Tolety², Mr Sahshidhar Komaravolu², Ms Bala Tripura Sundari², Dr Jyothi Obulapu<sup>1,2</sup>, Dr Suvarna Alladi<sup>3,2</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

**Background:** Dementia often gives rise to Behavioural and Psychological Symptoms (BPSD), posing challenges for the person and their carer. Fidget blankets, designed with tactile elements, address BPSD by providing sensory engagement and diversion. Restless hands find solace in these blankets and can reduce changed behavior. By offering a safe outlet, these blankets align with person-centered care principles, enhancing the well-being of people living with dementia. The calming effect, proves vital in managing BPSD, making fidget blankets an invaluable non-pharmacological intervention in dementia care.

**Aim:** This study seeks to assess the impact of fidget blankets on the BPSD. It also aims to examine the impact of these blankets on the quality of life of carers. We aim to uncover the tangible advantages of incorporating fidget blankets into dementia care, providing valuable insights into their practical benefits. At the same time helping carers to develop and make these blankets for their loved ones with dementia, in order to avoid the high cost of buying these dementia fidget blankets available in the market.

**Method:** The study employs a design, comprising a control group and an experimental group, each n=20. The research spans a duration of six months, pre-test and post-test evaluations are conducted for both persons with dementia and carers. Assessment tools like the Neuropsychiatric Inventory (NPI), Clinical Dementia Rating (CDR), Depression, Anxiety, and Stress Scale (DASS 21), Quality of Life (QOL), and Disability Assessment for Dementia (DAD) will be administered.

**Conclusion:** This study will carefully look at how fidget blankets as an intervention can help reduce the impact of BPSD on the person with dementia and their carer in an Indian setting.



## **Delusions in Lewy Body Dementia: Variations.**

#### **Dr Tolulola Olufunto Taiwo**

Red Deer Regional Hospital Centre, Red Deer, Canada

### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

Delusions in Individuals with Lewy Body Dementia.

**Background:** Lewy body dementia (DLB) is a common neurodegenerative condition. The core features of this disorder are Parkinsonism and perceptual disturbances; of which visual hallucinations are often the most commonly reported.

**Objective:** Lewy body dementia in patients referred for Persistent Perceptual Symptoms.

**Methods:** Retrospective cross-sectional survey of DLB patients in a community-based geriatric consultative service. We reviewed the clinical reports, including cognitive and behavioral assessment, and laboratory records of the patients referred over a 24-month period.

Reports of delusions of infidelity in all seen in outpatient clinic. We reviewed the records of all incident cases of Lewy body dementia (DLB) referred to the Geriatric Program from July 21 – July 2023. We examined the following data: Demographical data including age, gender, educational level and residential status were obtained. Additional data on cognitive scores (Mini Mental Status Examination, Montreal Cognitive Assessment and Frontal Assessment Battery) were obtained. Mood questionnaires were completed. We also obtained Behavioral Questionnaires (Neuropsychiatric Inventory and Cohen Mansfield Agitation Inventory) were completed.

The diagnosis was confirmed via FDG-PET brain imaging scan

**Results:** 21 patients were diagnosed with Lewy body dementia. 17 of these (80.95%) were males. The ages of ranged from 57 – 86 years. The referrals were against the background of persistent perceptual symptoms, predominantly delusions and suspected delirium. Visual hallucinations were present in 48.1% of cases. Paranoid delusions were more commonly reported. Delusions were present in 64.2% of the cases. The most common delusions were of foods being poisoned and suspiciousness around medications.

**Conclusions:** Lewy body disease is a possible cause of persistent delusions and should be considered in the evaluation of patients with suspected psychotic features.



# Wandering tendencies among people with neurodegenerative diagnoses from the caregiver's perspective

**Ms Gabriela Początek**<sup>1</sup>, **Ms Natalia Segiet**<sup>2</sup>, **Mrs Julia Drzazga**<sup>3</sup>, Prof Agnieszka Gorzkowska<sup>1</sup>, Prof Aleksandra Klimkowicz- Mrowiec<sup>2</sup>, Dr Alys Griffiths<sup>4</sup>, Ms Iria Cunha<sup>5</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

### **Abstract**

The aim of the study was to find the most common reasons for one of the most common behaviors - wandering behavior presented by patients with Alzheimer's disease and other forms of dementia. Those tendencies to walk are defined as aimless locomotion behavior. They are associated with an increased risk of falls, injuries, fractures as well as a risk of disappearance. Moreover, this behavior may cause additional stress and burden for caregivers.

10 caregivers of people diagnosed with dementia took part in a semi-structured interview and completed the ZBI questionnaire on caregiver burnout. The interview was based on a previously developed thematic interview guide adapted to the needs of Polish caregivers.

Guardians notice both advantages and disadvantages of wandering behavior. Caregivers of people diagnosed with dementia point out that specialists have little knowledge in this area and that they need to generate helpful and supportive solutions on their own. What's more, caregivers showing symptoms of burnout are less likely to support wandering behavior and feel more helpless when handling this issue. Those who try to support wandering behavior try to analyze the situations in which they occur and look for the safest forms of wandering in the optimal space.

Relatives of people with dementia feel that they have too little support when it comes to behavioral difficulties of their loved ones. It seems justified to create support groups where it would be possible to supervise individual forms of support for people with dementia and regulate caregivers' emotions related to their daily duties. This will allow for adequate support for people with a tendency to wander and will help fight caregivers burnout. It also seems reasonable to train medical staff so that they will be able to support caregivers in their efforts to provide patients with a safe environment.



## Network-based identification of miRNAs and transcription factors and in silico drug screening targeting delta-secretase involved in Alzheimer's disease

### Dr SALEEM IQBAL

Chu de Quebec Hospital Quebec, CANADA, quebec, Canada

### **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

#### **Abstract**

**Background:** Systemic approaches have been pivotal in miRNA research, uncovering their role in various clinical conditions, including Alzheimer's Disease (AD). AD is an age-related, progressive neurodegenerative disorder characterized by cognitive decline and the most common cause of dementia globally. The lysosomal protease  $\delta$ -secretase (LGMN or AEP) plays a crucial role in AD pathology by cleaving amyloid precursor protein (APP) and tau. Dysregulated miRNA expression has been observed in AD patients across different bodily fluids and tissues.

**Methods:** We utilized Protein-Protein Interaction (PPI) networks to analyze LGMN, identifying brain-enriched miRNAs such as hsa-miRNA-106a-5p and hsa-miRNA-34a-5p among experimentally validated miRNAs. Transcription factors targeting LGMN-associated genes were identified. Expression patterns of the LGMN gene were investigated, revealing prominent expression in various brain regions, particularly the frontal cortex. In silico drug design identified Oprea1 as a lead inhibitor for further AD therapy exploration.

**Results:** Among the 16 experimentally validated miRNAs, network analysis of LGMN and its associated miRNAs highlighted hsa-miRNA-106a-5p and hsa-miRNA-34a-5p as highly expressed in the brain. In silico high-throughput screening followed by XP docking identified Oprea1 as the lead inhibitor. Molecular dynamic simulations of the  $\delta$ -secretase-docked complex spanning 200 ns indicated a Root Mean Square Deviation (RMSD) of the protein  $C\alpha$ -backbone that increased to 1.20 Å within the initial 25 ns, stabilizing at approximately 0.6 Å for the remaining 170 ns. Radius of gyration (RGYR) analysis indicated sustained compactness throughout the simulations.

**Conclusion:** Network analysis of LGMN-associated miRNAs revealed two novel miRNAs with high brain expression. The study identified and characterized 10 transcription factors associated with LGMN. Expression Heatmap results indicated prominent and continuous LGMN expression in various brain regions, particularly in the frontal cortex. In silico drug analysis led to the identification of Oprea1 as a promising candidate for further investigation in AD therapy



# Evaluating EEG Complexity and Connectivity During Visual Stimulation as a Potential Insight into Amyloid Deposition in Alzheimer's Disease

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### **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

### **Abstract**

**Aims:** The CASBA™ Visual Evoked Potential protocol is designed to stimulate early visual processing pathways during the collection of EEG signals and has been shown to be predictive of amyloid deposition using standard ERP feature extraction. We evaluated the extent to which established Alzheimer's disease (AD)-informative EEG feature classes, such as complexity and connectivity, extracted from visually stimulated EEG data, correlate with amyloid deposition.

**Methods:** We analyzed 81 EEG recordings (resting and visually stimulated) from participants with subjective cognitive decline, mild cognitive impairment, and AD, along with CSF amyloid measures. Following preprocessing to remove noise and unwanted frequencies, recordings were segmented into epochs with each ERP epoch containing one stimulation trial. Connectivity (PLV and spectral coherence) and complexity measures (AMI, HFD, and entropy) were derived. Using PCA, epoch-based features were condensed and evaluated for links to amyloid deposition. Spearman's r for the top 20 PCs across each feature set was calculated, supported by permutation testing for p-values.

**Results:** Complexity features computed from posterior electrodes demonstrated a significant moderate correlation with amyloid deposition (r>0.40; p<0.01). Frontal electrodes complexity also showed noteworthy associations. Connectivity features, from posterior electrodes, showed significant moderate correlations with amyloid deposition (r>0.35, p<0.01). Interhemispheric temporal connectivity presented large correlations (r>0.55, p<0.0001). Notably, these correlations were present only for stimulated EEG while analogous features computed from resting state epochs substantially lacked these relationships.

**Conclusions:** These findings suggest that visually stimulated EEG may provide a more nuanced understanding of AD beyond diagnosis through their relationships with measures such as amyloid deposition which are expensive, invasive, and have limited availability. Moving forward, the predictive strength of these EEG metrics warrants deeper investigation, and additional data is essential for the validation of these findings.



# QEEG slowing down parallels the increase of Alzheimer's neuropathology

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### **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

#### Abstract

**Aim:** The EEG trace represents an indicator of synaptic activity, which is early involved in cortical degenerative processes. Through the mathematical processing of the trace (quantitative EEG-qEEG), it is possible to obtain different indices of synaptic dysfunction. The purpose of this study is to explore how qEEG can recognize the type and extent of neuropathological changes.

**Methods:** The EEG traces and brains belonging to 14 donors of the Abbiategrasso Brain Bank were analyzed. qEEG analysis considered the relative power distribution (RPD) of the frequency bands ( $\beta$ ,  $\alpha$ ,  $\theta$ ,  $\delta$ ) and the peak frequency (PF), i.e. the most represented frequency considering all the leads. The Kruskall-Wallis test was used for the comparison between groups.

**Results:** The clinical diagnosis included: 2 Mild Cognitive Impairment (MCI), 4 Alzheimer's Disease (AD), 6 mixed dementia (MD), and 2 Lewy body dementia (LBD). The neuropathological definite diagnosis demonstrated frequent co-pathologies, and some discrepancies with respect to the clinical diagnosis. Considering both clinical and neuropathological diagnoses, the comparison between groups revealed no significant differences in qEEG parameters. Nonetheless, a trend emerges towards a lower  $\beta$ -RPD and a higher  $\theta$ -RPD in cases with prevalent LBD pathology. Grouping based on the severity of AD pathology (2 low, 4 intermediate, 4 high) demonstrated significant differences depending upon the neuropathological scoring with a progressive decrease of  $\alpha$ -RPD (p=0.029) and PF (p=0.019), and an increase of  $\delta$ -RPD (p=0.020).

**Conclusions:** Due to the low number of cases and frequent co-pathologies, RPD and PF show low discriminatory capacity on etiology. Nonetheless, the presence of LBD seems to boost the EEG slowing, as described by others. The PF slowing down parallels the increase of AD pathology, representing an indicator for the degenerative load. As PF is a simple qEEG parameter, it can be useful for monitoring neurodegenerative burden and disease evolution.



Patient, clinician and stakeholder experience around the implementation of a digital cognitive assessment and blood based biomarker in the early detection pathway of a Scotland site in the Davos Alzheimer's Collaborative (DAC) program

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### **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

### **Abstract**

**Background:** Progress in biomarkers and disease state understanding have allowed the development of new innovations in diagnosis, and as a result, new treatment strategies aimed at slowing the progression of cognitive impairment or preventing symptoms if used early in the disease. The DAC global programme is testing how equipped current healthcare systems are for early detection and we will share clinician and patient experience of these novel tools (Linus Health's Core Cognitive Evaluation (CCE) digital cognitive assessment and PrecivityAD blood biomarker) which were introduced into NHS clinical pathways as part of the Scotland Flagship Quality Improvement Project. The use of blood biomarkers (BBM) as part of the diagnostic clinical pathway is a first for Scotland.

**Method:** Baseline and end of program surveys and semi-structured qualitative interviews with clinicians and feedback gathered throughout the project.

End of program semi-structured qualitative interviews with key stakeholders within the health system

Use of a locally developed questionnaire for patients around the digital cognitive assessment (DCA)

Focus Groups for patients and care partners focused on diagnostic process and use of DCA and BBM

**Impact and Conclusion:** Powerful learning is emerging and will be presented including early findings suggesting that patients are pleased to be receiving additional investigations as part of the DAC early detection pathway and engagement with a specialist program is seen as a positive. Practical lifestyle advice is more commonly mentioned than considerations around clinical value of early detection tools. Also learning around multiple considerations for the implementation of BBMs in practice in future. This work will contribute to the DAC program scaling learning globally to position healthcare systems to speed the latest treatments and innovations to those who need them. Additionally informing local pathways and the national work of Brain Health Scotland.



## Predicting tau subtypes of Alzheimer's disease with plasma biomarkers

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### **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

### **Abstract**

**Objective:** Subtypes of AD were defined into hippocampal sparing (HpSp AD, relative sparing of the hippocampus but high cortical load), limbic predominant (LP AD, high hippocampal load but lower load in association cortices), and typical (Typical AD, balanced between the hippocampus and association cortices) AD by the Flortaucipir positron emission tomography (PET), which was shown to be consistent with the counts of neurofibrillary tangles in neocortical and hippocampal regions at autopsy. This study is to test whether plasma biomarkers glial fibrillary acidic protein(GFAP), neurofilament light chain(NfL), or their ratio (GFAP/NfL) differ in tau subtypes of AD.

**Methods:** We included 106participants(cognitive unimpaired [CU, n=20], cognitive impaired [CI, n=86] from the Alzheimer Disease Neuroimaging Initiative (ADNI) study with plasma biomarkers(GFAP and NfL) and matched Flortaucipir PET imaging. Initially, we used preprocessed tau-PET imaging to define the subtypes of AD according to the Murray algorithm. Then, we compared the demographic characteristics, cognitive function assessments and distribution of plasma biomarkers between AD subtypes and CN. We applied multinominal regression models to evaluate the discrimination among three tau subtypes(LP/Typical/HpSp) with different biomarker combinations. Plasma analytes, GFAP and NfL, were measured on a single molecular array(Simoa) Quanterix platform.

**Results:** We found that 1) blood NfL levels were the highest in the LP cases and lowest in HpSp cases, while GFAP levels and the ratio(GFAP/NfL) were the highest in the Typical cases and lowest in HpSp cases. 2) 3)blood biomarkers, GFAP, NfL and GFAP/NfL, can distinguish AD subtypes. **Conclusions:** These findings consolidated the close relationships of blood biomarkers with cognitive function and tau pathology, supporting the hypothesis that GFAP and NfL were identified as potential predictors of AD subtypes.



## Fun with Friends - NTUC Health Multimodal Intervention Programme for community-dwelling seniors with dementia and mild cognitive impairment in Singapore.

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### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Introduction** Early psycho-social intervention helps decrease the risk of developing dementia in persons living with mild cognitive impairment (PLwMCI) and slow down the disease progression in persons living with dementia (PLwD).

**Aims** The Fun with Friends (FwF) programme aims to improve well-being, and social interaction and promote cognitive reserve for PLwMCI and neurogenesis for PLwD via weekly 3-hour sessions consisting of physical exercise, meal preparation, and multimodal interventions such as music, art and occupational therapy.

**Method** The pilot run recruited 13 clients from February to May 2022. Post-session surveys and qualitative feedback were collected from the clients and caregivers for quality improvement.

The FwF programme commenced in September 2022. Montreal Cognitive Assessment and Time Up and Go test are administered upon enrolment and re-administered every six months. The Engagement of a Person with Dementia Scale is used to observe clients' engagement.

**Results** More than 80% of clients reported enjoying the sessions in the pilot run. More than 90% of caregivers rated their loved ones enjoying the programme and found it beneficial. They would recommend the programme to others.

In the FwF programme, the clients' cognition is well-maintained over six months (M0=15.21 and M6=16.57). More than 85% of the clients score more than 4 out of 5 for engagement in positive domains and do not display negative engagement.

**Conclusion** The FwF programme is well-received by the clients and caregivers. It offers social structure and resources to meet their needs. Rolling out the programme to multi-sites will benefit more clients and caregivers.



## Do community-based singing interventions have an impact on people living with dementia and their carers? A mixed-method study

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### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

Psychosocial interventions such as music therapy have been shown to improve mood, quality of life and relieve stress for people living with dementia (PwD). Previous evaluations of singing interventions have largely focused on impacts for the PwD and not their families and those supporting PwD. They have also mainly only included care home residents and not those living within the community. This research evaluates the impact of singing groups for PwD and people who support them in both community and residential settings and also aims to examine barriers that may prevent or reduce access and engagement. The project aims to recruit 150 people with dementia and 150 carers attending singing services. The impact of two different singing intervention services, one which combines singing alongside physically engaging dance and one which includes a sociable lunch, will be examined using a mixed-methods approach. The impact of the services will be examined via the following outcomes: quality of life; neuropsychiatric symptoms such as agitation; social isolation; carer burden; and mood/ depressive symptoms in PwD and those that support them. Semi-structured interviews will be conducted with a subset of 40 people to further examine the impact of singing services with a specific focus on acceptability of the service, barriers to access and prolonged engagement and potential for remote delivery. Quantitative and qualitative findings will focus on the impact of the singing support services and emerging themes in relation to acceptability, accessibility and engagement. Findings from this research will be used to create recommendations for future service delivery of singing interventions.



## **Effectiveness of Cognitive Rehabilitation Program Based on Storytelling for the People With Dementia in the Community**

Mrs Yunhee Lee<sup>1</sup>, Dr Jeonglan Kim<sup>1</sup>, Mr Kyujoon Kwon<sup>1</sup>, Miss Kyoungyoung Park<sup>2</sup>, Mrs Suhyun Park<sup>3</sup>, **Ms Daeun Kim**<sup>1</sup>

<sup>1</sup>Sejong Dementia Center, Sejong City, Korea, Republic of. <sup>2</sup>Jungwon University, Chung-cheong bukdo, Korea, Republic of. <sup>3</sup>Yeoju Institute of Technology, Gyeonggi-do, Korea, Republic of

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Background and objectives of the study:** The purpose of this study was to verify the effectiveness of cognitive rehabilitation programs based on storytelling for people with dementia at home and to provide basic data for the use and distribution of programs within the community.

**Methods:** The study was conducted by face-to-face interview at home on 33 people with dementia from June 2020 to October 2021, once a day for 60 min, 5 times a week for a total of 6 weeks. Cognitive function, depression, balance function, self-esteem, and quality of life were measured before and after the intervention.

**Result:** Comparison before and after cognitive rehabilitation program based on storytelling revealed that cognitive function (p<.001) and quality of life (p<.05) significantly improved, whereas depression (p<.001) significantly deteriorated.

**Conclusion:** In conclusion, a cognitive rehabilitation program based on storytelling is a medium that promotes voluntary participation of people with dementia and is effective in maintaining cognitive function and healthy life of people with dementia at home by inducing positive interactions between the collaborator and participants..



# Utilizing social prescriptions to promote the well-being of individuals with dementia in urban areas-Taipei model.

**Mrs Shin-Ting Chen**<sup>1</sup>, Dr Chien-Liang Liu<sup>1</sup>, Mrs Shao-Ping Lin<sup>1</sup>, Ms Yi-Chieh Chu<sup>1</sup>, Mr Shih-Yu Hung<sup>2</sup>, **Ms Wen-Chen Kuo**<sup>3</sup>, Dr Su-Wei Fan<sup>4</sup>

<sup>1</sup>Taipei City Hospital Dementia Center, Taipei, Taiwan. <sup>2</sup>National Taiwan Museum, Taipei, Taiwan. <sup>3</sup>National Symphony Orchestra, Taipei, Taiwan. <sup>4</sup>Taipei Botanical Garden (TPBG), Taiwan Forestry Research Institute, Taipei, Taiwan

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Aims:** This study aims to introduce how Taipei City Hospital Dementia Center implements the dementia social prescriptions and the positive effects it has on dementia patients and their families.

**Method:** This study introduces how Taipei City Hospital Dementia Center assesses dementia patients and prescribes social prescriptions. The link workers in the hospital give patients a referral to the resource providers (social and cultural institutions), such as concerts (National Symphony Orchestra), museums (National Taiwan Museum), and botanical gardens (Taipei Botanical Garden) in Taipei City. Alternatively, it may involve self-referrals by prescription users to participate in these resource providers.

**Results:** Through the assessment by Taipei City Hospital Dementia Center, it provides service connections and case referrals while simultaneously training organization staff and volunteers.

Through specialized educational training, it strengthens the dementia health literacy of the hospital's collaboration with "Dementia Social Prescriptions" and the "Dementia-Friendly Community" as a "Dementia-Friendly Organization." This enhances the skills for responding to and accommodating dementia patients, reduces dementia stigmatization, and minimizes social exclusion effects.

**Conclusion(s):** Taipei City Hospital Dementia Center will further develop dementia-friendly organizations and appropriate assessment tools.

It will continue to referral patients to dementia-friendly organizations, empowering organizations to plan programs that better cater to dementia patients and are more conducive for patients and their families to participate independently.

This effort aims to make dementia-friendly organizations contribute to the care and support of vulnerable populations in society.



### Training our college music students for interactive musicmaking in dementia care

Dr Allison Gagnon, Ms Rebecca Nussbaum

UNC School of the Arts, Winston-Salem, NC, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

Community engagement is an increasingly relevant focus of musicians' training, and university music programs are evolving from the traditional models that train performers and teachers, towards curricula that include citizen-artist opportunities. At the same time, music as an effective means to engage those who are living with dementia is gaining ever more attention.

Music Between Us offers resources to train music students for interactive musicmaking with those living with dementia. Now in its fifth year, Music Between Us began as a pilot project in 2019 through ArtistCorps, the University of North Carolina School of the Arts' community engagement program. It is led by Dr. Allison Gagnon, faculty mentor from the School of Music, and Rebecca Nussbaum, director of ArtistCorps. We partner with the Williams Adult Day Center in Winston-Salem, North Carolina and the program has evolved from its pilot year and through pandemic challenges. Our experience with participants at WADC was the basis for the first edition of our MBU Program Guide\* that was first made available in the fall of 2022. It comprises resources scalable for college schools of music. Included are the following:

- guidance for interacting effectively with those living with dementia and their caregivers;
- information about the power of music to counteract the social isolation that can characterize life with dementia;
- tips for building sessions and playlists according to available resources; and
- ideas for connecting with community partners that will welcome music students into care settings.

Engagement is a reciprocal relationship in which both participants and team members give to each other, and everyone is uplifted! Please join us to learn more about *Music Between Us*, and our goal to share it widely with college music programs.

\*The MBU Program Guide is being revised later this academic year.



### Music-making for the well-being of older people with dementia: Preliminary findings from the implementation of a community music intervention in residential care facilities

Mrs Rafaela Troulou, Prof Lida Stamou

University of Macedonia, Thessaloniki, Greece

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Aims:** Although music-making is well-acknowledged in the literature as an effective non-pharmacological approach in dementia care, few studies have focused on community music-making in care settings. Community music refers to the active engagement of participants in shared group music-making experiences. The present study aimed at investigating the effect of a community music intervention on the well-being of older people with dementia in residential care.

**Method:** The community music intervention was conducted in two nursing homes in Greece from July 2022 to May 2023 and involved a total of 40 music sessions. 35 older people participated (12 with dementia, 14 with some type of cognitive impairment, and 9 with intact cognitive abilities). The music sessions followed a similar structure and included music activities such as singing and rhythmic playing on percussion instruments. The collection of songs used remained mainly stable. All sessions were videotaped. Semi-structured interviews were conducted with two members of the care staff and two assistants of the facilitator/ researcher.

**Results:** Preliminary qualitative research data obtained from observation of video recordings and thematic analysis of semi-structured interviews suggest that: (1) the intervention served as a form of non-verbal interaction and socialisation between participants with different cognitive states, (2) the similar structure of the sessions and the stable repertoire seemed to foster emotional and musical responses from people with dementia, (3) the intervention helped to alleviate some negative symptoms that might accompany the experience of dementia, such as agitation and wandering.

**Conclusion:** This study contributes to our limited knowledge of the impact of community music-making on the well-being of older people with dementia in residential care. Further research is needed to examine whether the use of a stable structure and repertoire could be key features in the design of successful music interventions for people with dementia.



### Application of "Live For Today Card Set" Combined with Nonpharmacological Interventions in Community-based Dementia Service Stations

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Taipei City Psychiatric Center, Taipei, Taiwan

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Background:** and purposes: The "Live For Today Card Set" represents a cross-disciplinary collaboration, blending art, culture, and medical expertise, serving as an art-assisted therapy tool for sharing life experiences, enhancing cognitive function, and self-awareness. This research explores the feasibility and acceptability of using the "Live For Today Card Set" to design art and physical activities for elderly individuals with dementia in the community.

**Methods:** This program, centered around the "Live For Today Card Set," includes four art activities and five physical activities, each lasting two hours and led by two occupational therapists. These sessions comprise a warm-up (20-30 minutes), the main activity (70-80 minutes), and a sharing and discussion segment (10 minutes). The goals are to improve attention, physical fitness, hand dexterity, enjoyment, and verbal expression in dementia patients.

**Results:** Ten elderly individuals with mild to moderate dementia participated, showing positive outcomes. Despite limited exposure to artifacts from the National Palace Museum, they displayed consistent interest and engagement. The varied card themes encouraged discussion, particularly benefiting those with higher educational backgrounds, who shared their art-related knowledge. The card size was suitable for dementia patients, enhancing readability compared to traditional games.

**Conclusion:** The "Live For Today Card Set" offers versatile applications and can be tailored to local characteristics, making it a valuable non-pharmacological intervention tool for community-dwelling dementia patients. This approach contributes to maintaining and enhancing cognitive function, ultimately delaying disability and cognitive decline.



## Seniors Thrive: Meaningful Activities for Mental Health at a Social Center in Portugal

**Dr Sabine Krofczik-Wilhelm**<sup>1</sup>, Ms Laura Acciaioli<sup>2</sup>, Mr Pedro Amado Gomes<sup>2</sup>, Ms Maria Eugenia Brandulo<sup>3</sup>, Ms Victoria Mitchell<sup>4</sup>

<sup>1</sup>Brain Loves Circuits, Azeitao, Portugal. <sup>2</sup>Nature Affairs for human Growth, Quinta Do Anjo, Portugal. <sup>3</sup>Tango Terapia em Portugal, Lisbon, Portugal. <sup>4</sup>6 Senses Yoga, Sesimbra, Portugal

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

A healthier, more engaged generation of older adults has the potential to contribute broadly to a flourishing community of their choice. To shape the future, we need to understand today's older adults and how their health is being shaped by social and personal influencing factors and how we can support them based on individual needs.

We partnered with a social center in Quinta Do Anjo, a small rural parish in Portugal with 14K habitants 40 km from Lisbon. The day center has capacity for 35 older adults and at the time of the project a diverse group of 18 people were visiting the center daily. Activities were only available insignificantly due to lack of staff and funding and the team noted mental health issues, cognitive decline, and apathy amongst the older adults. A diverse group of 8 older adults was interested and willing to participate in multifaceted meaningful activities over a period of 4 months which included Tango-, Yoga and Aromatherapy as well as dog-assisted therapy and traditional Portuguese games.

The participants completed the Quality-of-Life AD questionnaire (Canavarro et al. 2009, Portuguese version) with the objective to demonstrate that regular meaningful activities can improve the Quality-of-Life of older adults and improve the overall sense of belonging to the community.

During the project, the team observed an improvement in the people who participated in the sessions. In addition, a qualitative analysis of the answers given in the questionnaire indicates that all participants reported improvements in the dimensions "life as whole", "living situation" and "physical health", leading us to conclude that the activity achieved the objectives. Please watch the video to see a short summary of the project Seniors Thrive: <u>Meaningful Activities for Mental Health</u>.



### Music and Memory in Dementia: The Impact on Quality of Life

### **Dr Deepa Vinoo**

NY City Health +Hospitals/Coler, NY, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

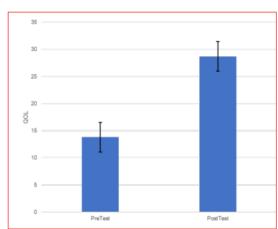
### **Abstract**

**Aim:** To evaluate the impact of the Music and Memory program on the quality of life of residents with dementia.

**Background:** The long term care facility has six memory care units with 150 dementia residents. Managing dementia-related behavior was a challenge for the memory care unit team. The key stakeholders have done a gap analysis and identified a high priority need to improve person-centered programs such as the Music and Memory program for people with dementia to enhance their quality of life.

**Methods:** The data collection process was pre- and post-implementation of the Quality of Life-AD survey to recreational therapists and nurses of the memory care units since the participants had cognitive impairment.

The setting is 815-bedded geriatric facility, the population included 150 residents with a diagnosis of dementia



**Intervention:** The personalized playlists were played for selected residents with dementia for a minimum of one hour each day, six days a week for nine weeks

**Results:** The paired sample test showed that post-test QOL scores were (M =28.7000, SD =2.71006) higher than the pre-test QOL scores (M =13.8000, SD =2.97396) which indicated that the Music and Memory program had a significant effect on participants with dementia on their quality of life compared to traditional health care model in 8-10 weeks. The t-test comparing the pre-implementation versus the post-implementation QOL AD scale total scores was statistically significant (p < 0.001).

**Conclusions:** The findings confirm that Music and Memory programs enhance the quality of people with dementia in nursing homes. implementation of Music and Memory intervention reduced neuropsychiatric symptoms of dementia. Music and Memory program enabled the memory care unit team to manage the challenging behavior of dementia.



### Digital solutions for the delivery of Cognitive Stimulation Therapy

**Ms Lily Mainstone-Cotton**, Dr Nahid Zokaeri, Dr Simon Nielsen, Ms Simay Bayatli

Brain+, Copenhagen, Denmark

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

The benefits of Cognitive Stimulation Therapy (CST) delivered twice a week for the duration of 7 weeks to people with dementia are well documented. However, various factors influence the extent to which CST is effective in practice. One possible factor is that identifying and delivering cognitively well-suited activities to a mix group of patients with varying levels of impairment is very challenging, leading to sessions that are either too easy or too difficult and hence leading to insufficient cognitive stimulation for some patients. Importantly, developing such activities is time-consuming, adding extra cost to an already over-worked health system. This has indeed resulted in some CST providers only offering one single session per week, which studies have found is not the correct dosage of stimulation to ensure cognitive benefits.

Brain+ has developed a digital solution to directly address the mentioned barriers by providing greater guidance to practitioners through activities tailored to differing dementia severities, alongside reducing the time necessary in preparation for sessions. The product was developed through multiple steps. Firstly, a panel of international CST experts were consulted on acceptability and cognitive suitability of each activity, followed by a wide scale rating of activities on cognitive suitability from international practitioners. A small-scale feasibility study is currently investigating the usability and acceptability of the product, which will be followed by a larger clinical trial to assess the clinical outcomes of people with dementia alongside the impact on preparation time and ease for practitioners. This study will provide a strong foundation to build a standardised approach for CST and further offer novel insights in the level of consensus amongst experts and practitioners. If successful, the final product will support large-scale implementation of CST and critically reduce variability in outcomes.



## Weaving Memories through Collaging: A Storytelling Collaboration with My Mom

Mr Jason C Andrew<sup>1</sup>, Ms Pamela Andrew<sup>2</sup>

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### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

Collaging - the process of combining various visual and textual elements to create a new medium - has emerged as a therapeutic tool for my mom following the death of her life partner, her everything, Virginia; transforming their shared home into an expressive canvas. Her new artistic style unfolds with uninhibited fervor, taking the form of folk art as she confronts grief, loss and her love of family.

In 'Every Day is a New Day,' I collaborate cross country with my mom as she journeys into collaging, revealing the impact of blending pictures, text, and original art. This fusion isn't merely a creative endeavor; it has become a therapeutic tool that enhances her cognitive abilities while nurturing her emotional well-being.

As my mom explores therapeutic art, she unravels many unseen layers of her life that appear lost in time. Reflecting on her immigrant upbringing, the walls of her home have been transformed into an autobiographical canvas revealing her unfiltered strength and resilience.

Using my images as an eye into her world, we witness her unwavering embrace of this new chapter. Each image, cut into shapes, highlights the people in the frame and captures a moment in Mom's narrative. Through this process, we witness her unwavering embrace of this new chapter - one that seems to reset with each passing day.

Though this is not the focus of this process, my mom has dementia. Collaging offers her a multidimensional therapeutic approach. While this creative process is helping her process grief, it also improves her cognitive abilities and provides a platform for her emotional expression. Most importantly, collaging helps my mom communicate with caregivers and family members in a newfound medium - it has deeply enhanced her overall quality of life.



### SonoraMente, a therapeutic choir for dementia and caregivers

Dr Alice Bencivenni<sup>1</sup>, Dr Alice Balboni<sup>1,2</sup>, **Dr Sara Annibali**<sup>3</sup>, Dr Marta Vinci<sup>1</sup>

<sup>1</sup>Walter Vinci Onlus, Milano, Italy. <sup>2</sup>RSA Focris, Saronno, Italy. <sup>3</sup>Università Cattolica, MILANO, Italy

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

### **Abstract**

**Background:** For more than a decade the scientific literature has highlighted music therapy as a powerful tool for reducing cognitive decline in dementia, and a valuable ally in improving the quality of life and relationships of patients and their caregivers. In particular, music therapeutic interventions through choral singing confers a protective effect that can alleviate symptoms, prolong the patient's cognitive health and independence, and partly delay the transition to long-term care.

**Aims:** SonoraMente is a music therapy and choral singing format structured for people with dementia and their caregivers, active in Milan since 2016. It takes place in a non-institutionalised context, with rehearsal sessions lasting two hours every week, for 10 months a year. Some of the objectives are: reduction of BPSD, stimulation of residual cognitive and executive functions, fostering of relationships and sharing with others, improve quality of life, promote the reduction of stress of the caregivers.

**Method:** 3 assessments were carried out (pre-, post-, follow up) with 5 pairs of patients-caregivers. Neuropsychological scales were used to assess the cognitive and behavioral profile of patients, together with scales of quality of life, social support and burden for the caregivers.

**Results:** our results show an improvement of quality of life and perception of social support, combined with a reduction of BPSD symptoms, both in the post-intervention assessment and in the follow-up.

**Conclusions:** clinical evidence confirms the effectiveness of music therapeutic intervention in managing relational distress among people with dementia and their caregivers, also highlighting the relational group dynamics created by the choir and the improvement in the quality of life of those involved. The small number of cases analysed in this presentation allows only a qualitative comparison, but the results presented are encouraging, suggesting the importance of conducting further studies on larger populations and keep promoting this important project.



### Key drivers in developing creative arts and cultural engagement as a means of supporting people living with dementia and their care partners in the UK

#### Ms Maria Stanislawa Pasiecznik Parsons

Creative Dementia Arts Network, BRISTOL, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

In the UK, increasing numbers of people living with dementia and their care partners participate in creative arts including drawing, painting, craft, digital arts, music, singing, dance and movement and drama and engage in cultural activities such as visiting museums or going to the theatre. Opportunities to participate are provided by arts organisations, arts venues or led by arts, health and wellbeing practitioners and take place in hospitals, social care housing, care homes and in the community.

Several major drivers for the growth of creative arts and cultural engagement have been identified including increased prevalence of dementia and rising demand for NHS and local authority services, resulting in unmet needs such as social isolation, health, management of an individual's BPSD, meaningful day time occupation and care partner support.

UK policy makers have recognised the contribution that creative arts can make in meeting such needs. Creative Health Associates now work in local service commissioning teams to ensure creative arts are available people living with dementia in line with the recommendations of Creative Health: The Arts for Health and Wellbeing (2017) whilst Public Health England has rolled out Social Prescribing, a service that enables GPs, nurses and link workers to refer patients to non–clinical services including local creative arts.

These initiatives have accelerated given better evidence of the social, cognitive and psychological benefits of creative arts with more funding allocated to research studies investigating the impact of creative arts in reducing BPSD and improving quality of life for people living with dementia. Given the absence of effective treatments for the condition, and governmental directives to reduce inappropriate prescribing of antipsychotics, especially in care homes, non-pharmacological and psychosocial approaches to dementia such as creative arts are proving central to supporting personhood, challenging stigma and the inclusion of people living with dementia.



### Comprehensive Geriatric Evaluation focusing on Dementia/ Alzheimer's Care

Dr Dohwa Kim<sup>1</sup>, Mrs Jennifer M Amico<sup>2</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

Kaiser Permanente (KP) is among the nation's largest and highly regarded healthcare delivery organizations. KP is an integrated healthcare delivery system comprised of Kaiser Foundation Hospitals, Kaiser Foundation Health Plan, and physicians in the Permanente Medical Groups. One in four insured Californians belongs to a KP Health Plan. Nearly 30% of KP members who visit KP Woodland Hills are aged 65 or older, which places KP Woodland Hills as the largest KP service area in SCAL to provide care for older adults. The Department of Geriatrics comprises Palliative Care, Hospice Care, Community Care Programs, and a Memory Care clinic (GPCCM). Memory care is a subspecialty referral-based outpatient clinic focusing on evaluation and diagnoses for various cognitive impairments.

Patients are seen by a multidisciplinary team comprised of a geriatrician, medical assistant, case manager, social worker, and pharmacist. First, the medical assistant collects vital signs and provides cognitive testing to the patient. Second, the Pharmacist reviews all the patient's medications, including over-the-counter medications to avoid medication that may affect memory and polypharmacy. Third, the social worker assesses the patient's mood and resources for various needs. Fourth, the Geriatrician gathers all information and examine the patient to diagnose the cause of memory loss and provide a plan for management. Fifth, the case manager works with the interdisciplinary team to follow up on the care plan and monitor any hospitalization and appropriate follow-ups. GPCCM created an operational guideline to spread best practices and efficiently deliver high-quality care.



# An ecological virtual house for the assessment of general cognitive deficits and activities of daily living in people with Mild and Major Cognitive Impairment: Design of the battery

Mr Nikolaos Altanis<sup>1</sup>, Mrs Eleni Poptsi<sup>2,3</sup>, Prof Andreas Symeonidis<sup>1</sup>, Dr Emmanouil Tsardoulias<sup>1</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

**Introduction:** The reliable diagnosis of minor and major neurocognitive disorders (MMNCD), as well as the investigation of the difficulties in Activities of Daily Living (ADL) in realistic conditions, are ultimate targets in the field of neurosciences. During the past years, several digital applications have been developed, aiming to replace the standard neuropsychological assessment performed with paper/pencil. Target: The design of an ecological digital environment (a virtual house) by utilizing a PC, through which: a) the general cognitive abilities will be evaluated, and b) the capability of people with MMNCD for the implementation of complex and simple ADL in realistic conditions will be assessed.

**Methods:** The virtual house comprises five rooms (kitchen, living room, bedroom, bathroom, balcony). During the administration of the virtual house's tasks the examiner operates the PC, whereas the examinee has to implement several cognitive tasks of episodic memory, aspects of attention/ executive function, word comprehension/production, and social cognition, by reacting to the task's requests. The scenarios behind the tasks are ecological, since they derive from the subjective cognitive complaints of people with MMNCD in real life, as documented via metacognitive and self-report questionnaires.

**Results:** The virtual house is expected to have good discriminant validity in the diagnosis of minors from major cognitive disorders and in showing with high accuracy the ADL's difficulties in realistic conditions.

**Conclusion:** The virtual house could be a helpful diagnostic tool, and also a helpful guide for designing effective cognitive training programs for people with MMNCD.



## Discourse Informativeness in Alzheimer's Dementia and Mild Cognitive Impairment

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Aims:** In recent years, the assessment of language abilities of persons with cognitive deficits focuses on discourse abilities. Specifically, the analysis of informativeness proves to be an effective tool. It is an assessment that combines the structuralist and functionalist approach to discourse analysis – that is, an assessment reflecting on both macrostructure and microstructure of discourse. One of the time-efficient options for assessing informativeness is Main Concept Analysis (MCA). The aim of the research was to apply MCA in a sample of Slovak speaking participants.

**Method:** The research sample consisted of 25 people with Alzheimer's disease, 25 people with mild cognitive impairment (MCI) and 25 healthy controls. Spontaneous speech samples were obtained using a picture description task. A checklist of 11 concepts for this picture was determined. In the transcripts of the research sample, the occurrence of these concepts was evaluated.

**Results:** Significant differences were found in the performances of the three research groups (p < 0.001;  $\epsilon 2 = 0.422$ ). The most concepts were expressed by persons from the control sample ( $\bar{x} = 7.84$ ). People with MCI followed ( $\bar{x} = 6.16$ ) and the group of people with AD expressed the fewest concepts ( $\bar{x} = 3.96$ ). Significant differences were found when comparing the control sample and both clinical samples – MCI (p = 0.016) and AD (p < 0.001) and when comparing the performance of clinical samples to each other (p = 0.006).

**Conclusion:** MCA could also be applied in the Slovak-speaking population. Based on the results, it was possible to differentiate both AD and MCI from healthy controls, as well as to differentiate the AD and MCI from each other based on their specific performance. The aim of further research should be a more detailed processing of MCA for other elicitation materials commonly used in Slovak practice.



# LANGaware: Biomarker workflows for classifying neurodegenerative and affective disorders across languages and severity levels

**Dr Vassiliki Rentoumi**<sup>1</sup>, Prof Evangelos Vassiliou<sup>2</sup>, Dr George Paliouras<sup>3</sup>, Dr Dimitra Sali<sup>4,1</sup>, Mr Admir Demiraj<sup>1</sup>, Dr Nikiforos Pittaras<sup>3,1</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

**Aims:** A wide range of neurodegenerative disorders impair communication faculties, manifested as subtle changes in speech. Following trends in Machine Learning (ML), recent works pursue classification of such disorders by developing biomarkers useful for cognitive status description. However, investigations that gauge biomarker applicability on cases of radically different impairment / symptom severity have been under-investigated. In this work, we build upon previous research and evaluate LANGaware's biomarker suite in the drastically different tasks of Dementia and Depression classification against appropriate Healthy Controls in a multi-language setup.

**Method:** We utilize audio recordings and transcripts from patient responses to verbal cognitive assessment tasks. These are analyzed with LANGaware's multimodal biomarker pool, producing scores that quantify vocal, linguistic and grammatical usage proficiency, structure and patterns, by applying both statistical analysis and explainable template matching. Biomarkers activations are fed to ML workflows composed of gradient boosting learners that employ feature selection, filtering and ensemble-based learning to arrive at configurations best suited for discriminating the disorder of interest. The pipeline is evaluated using a standard train-test and cross-validation setup.

**Results:** Experimental results indicate that our method achieves weighted-F1 test scores of 82.49% for Greek Dementia classification, using a train/test dataset of 1271/624 instances and 80.28% on 570/243 English data. We use the same pipeline and biomarker pool for Depression classification, reaching 74.03% and 71.36% performance scores, obtained from 73/31 and 652/42 available train-test data, for Greek and English respectively.

**Conclusion:** The above findings show that LANGaware's biomarker pool is applicable to diverse disorders, achieving a weighted-F1 performance above 71% and serves as a valuable decision support tool for early diagnosis, enabling proactive care, symptom management, and enhanced patient quality of life. Future research will expand the evaluation to more disorders and modalities.



## Development and Evaluation of Cognitive Impairment Screening Tool Based on Eye Tracking Technology.

Miss Shifang Zhang, Prof Qiaoqin Wan

Peking University, Beijing, China

### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

**Aims:** This study aimed to develop a cognitive impairment screening tool based on eye tracking technology (ET-CIS), and apply ET-CIS to community-dwelling older adults to evaluated its screening performance.

**Method:** ET-CIS were developed based on through systematic review, pre-experiments and expert consultation. We recruited older people in the community from July 2022 to November 2022 and collected data including demographics data, Montreal cognitive assessment, the mini-mental state examination, ET-CIS. The t-test and correlation analysis were conducted to screen out statistically significant parameters with of ET-CIS. The screening models were constructed using standardized score assignment, binary logistics regression analysis, and decision tree model in the training set, and were applied in the validation to evaluate the screening performance. The best model was selected as the final scoring model.

**Results:** ET-CIS was constructed including applicable objects, pre-assessment preparation, screening dimensions, specific experiments and parameters. A total of 301 subjects were included, including 163 in the cognitively normal group and 138 in the cognitive impairment group. The results showed that the decision tree model results showed that the sensitivity of the training set was 0.752 and the sensitivity of the validation set was 0.818. We use the decision tree model as the final model.

**Conclusions:** In this study, ET-CIS was developed including the evaluation of memory function, executive function, visuospatial function and abstract function. The screening model of ET-CIS in community-dwelling older people showed good discrimination, which demonstrated it could be used to effectively screen cognitive impairment in the community in the future.



### Prevalence of Cognitive Impairment in Elderly Patients with End-Stage Kidney Disease Undergoing Hemodialysis in a third level private hospital in Monterrey, Mexico

**Dr Aníbal Gutiérrez Torres**, Dr Karina Rodríguez-Quintanilla, Dr Rogelio Maya-Quinta, Dr Alejandro Valdes-Cepeda, Dr Alejandro Valdes-Canales

Instituto Tecnológico y de Estudios Superiores de Monterrey (ITESM), Monterrey, Mexico

### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

**Introduction:** The ageing population with Chronic Kidney Disease (CKD) has been increasing in developing countries [1]. Prevalence of geriatric syndromes, including cognitive impairment, in this population remains unknown since patients undergoing Hemodialysis (HD) seldom receive a Comprehensive Geriatric Assessment (CGA) [2].

**Methodology:** In patients 50 years and older, receiving HD in a private third level hospital in northern Mexico, we applied a CGA consisting of functionality (Barthel and Lawton & Brody), comorbidity (Charlson Index), cognition (MoCA), depression (Yesavage), frailty (CFS), nutrition (MNA-SF), sarcopenia (EWSOP2), falls, and quality of life (OPQOL-Brief).

Of 52 patients in the HD unit, 35 were eligible for the study. 9 patients did not gave consent to participate in the study, resulting in a population of 26 patients.

**Results:** Mean age of the population was 68.85 years and 61% were women. Comorbidity was severe (Charlson  $\geq$  5) in 84% of patients. The majority of patients (34%) reported having a very bad quality of life.

Taking a cut-off point for cognitive impairment of 26 points on the MoCA scale (with a sensitivity of 80% and specificity of 75%) [3], 84.6% of the patients presented cognitive impairment, this made cognitive impairment the second most common geriatric syndrome presented in this population.

By further stratifying the MoCA score into mild (18 to 25 points), moderate (11 to 17 points) and severe (< 10 points) cognitive impairment [4], the majority of the population presented mild cognitive impairment (77.3%), followed by moderate cognitive impairment (13.59%) and severe cognitive impairment (9.1%), as demonstrated by Table 1.

Table 1.- Severity of Cognitive Impairment by MoCA

**Conclusion:** Our findings revealed that cognitive impairment was the second most common geriatric syndrome presented in elderly patients with ESKD undergoing HD. We also found a higher incidence of cognitive impairment (84.6%) than what has been reported internationally in similar populations [2].

Severity of cognitive impairment by MoCA score	%
Mild Cognitive Impairment	77.3
Moderate Cognitive Impairment	13.59
Severe Cognitive Impairment	9.1



# The Experience of Dementia Diagnosis in Individuals from Ethnic Minority Groups in the UK

### Ms Emily Vivienne Budden

Brighton & Sussex Medical School, Brighton, United Kingdom. Sussex Partnership NHS Foundation Trust, Brighton, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

**Aims:** Providing access to timely dementia diagnosis is a key policy directive for many countries as they seek to support people to live well with the condition. However, in the UK minority ethnic groups are underrepresented in dementia diagnosis, and diagnosis is often received in the latter stages of the condition. As dementia cases in minority ethnic groups are expected to continue rising, it is crucial to better understand diagnostic experiences to inform future policy and education. This systematic review and qualitative meta-synthesis aimed to update previous literature, applying a novel analysis framework to understand barriers and facilitators to diagnosis for people from minority ethnic groups in the UK.

**Method:** A pre-registered systematic literature search was conducted. Qualitative studies were eligible that examined the experiences of people from UK minority ethnic groups seeking a dementia diagnosis. Data were extracted and a deductive thematic synthesis was performed to map findings to six domains of the Candidacy Framework; a widely used theoretical framework that conceptualises access to healthcare as an intricate process involving individuals, providers and institutions.

**Results:** From 251 papers reviewed independently by two researchers, 10 met the eligibility criteria. The analysis highlighted issues in domains of the Candidacy framework regarding barriers to accessing a timely dementia diagnosis. This included issues with recognising dementia symptoms and identifying need for services due to stigma and familial care expectations, service navigation issues due to a lack of awareness, poor experiences of services, and a lack of culturally sensitive care.

**Conclusion:** There are individual and culturally specific barriers to diagnosis for minority ethnic groups in the UK which may prevent those with dementia and their carers from prompt help-seeking. It is necessary for institutions and providers to offer more culturally sensitive health and care services and education to meet the needs of these populations.



### Cognitive Health and Functional Abilities of Illiterate Older Peruvians

### Dr Maritza Pintado-Caipa

Global Brain Health Institute, Lima, Peru. Instituto Lixwi-Salud Neurointegral, Lima, Peru. Instituto Peruano De Neurociencias, Lima, Peru

### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

**Background:** It is estimated that approximately 7% of the population in the capital city of Lima lives with dementia but there is little to no knowledge of the cognitive health of older Peruvians living in urban and rural centers outside Lima, especially the illiterate, who constitute around 41% of this population. Peru is home to tremendous social and geocultural diversity, which may mitigate the worrisome dementia risk assessment described above. It is interesting to note that many older Peruvians remain active and functionally independent in their respective communities for long periods of time, despite expected cognitive decline based on age and other risk factors.

**Method:** We recruited 40 participants from 4 rural and urban cohorts from the Andes and the Jungle. We conducted gold standard evaluations to arrive at a multidisciplinary consensus diagnosis of suspected normal aging, subjective cognitive impairment, mild neurocognitive disorder (or mild cognitive impairment), or major neurocognitive disorder (or dementia). The analyses for aim 1 is purely descriptive and we will report mean and standard deviations on the goldstandard and brief cognitive assessment (MMSE, RUDAS, BHA, and adapted PFAQ) measures by region, rural/urban, and diagnostic group. For aim 2, we used the Receiver Operating Characteristic curve analyses to explore the sensitivity and specificity the MMSE, RUDAS, and BHA compared to gold standard diagnosis in each of the 4 cohorts and also combined across all subjects; we will also determine sensitivity and specificity of the Adapted PFAQ compared to gold standard diagnosis and CDR. For aim 3, we conducted a regression analysis predicting a global cognitive composite score (based on gold standard neuropsychological testing).

**Results:** We are finalizing the process of data collection, ready for statistical analysis. This has been a job full of challenges, and also to see opportunities we have to address on brain health.



# Title: Machine learning and Magnetic Resonance Imaging for early dementia diagnosis, a systematic review in Mauritius

### **Dr Geeta Devi Dorkhy**

Association Alzheimer and Dementia, Mauritius, Port Louis, Mauritius

### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

Mauritius is witnessing a rise in dementia and Alzheimer's disease and it is a global challenge. There is approximately 19% of elderly people above 60 years of age. Therefore, calling for urgent attention and tailored interventions especially in low-middle income countries before a global pandemic declared. This abstract, addresses the use of machine learning technique (ML) in conjunction with Magnetic Resonance Imaging (MRI) for early detection of dementia.

**Method:** A comprehensive literature search was conducted encompassing studies up to 2022, to identify research articles, systematic reviews related to integration of ML algorithms and MRI in early diagnosis of dementia. The selected studies were critically evaluated for data augmentation techniques, image processing technique, features selection and extraction, features representation and classification.

**Results:** There are promising results with use of ML and MRI for early diagnosis of dementia and its various forms, such as vascular dementia and frontotemporal dementia. Techniques such as convolutional neural networks (CNN) have promising results in extracting spatial neural patterns in MRI scans, enabling precise classification and prediction of dementia.

Multimodal imaging techniques has been used by combining MRI with Positron Emission Tomography (PET) scan for enhanced diagnostic accuracy.

**Discussion:** The use of ML algorithm in conjunction with MRI imaging for early diagnosis of dementia represents a scientific revolution. This technique offers a potential to augment traditional diagnostic method and to provide an accurate and timely detection for dementia. There are challenges for large dataset and interpretation models in ML.

**Conclusion:** This abstract is a review of on-going research with ML and MRI. There are promising results to multidisciplinary approach for early diagnosis of dementia and for the patient outcomes.



### **Exploring the Digital Frontier in Cognitive Assessment: Opportunities and Limitations**

Ms Sara Wallén<sup>1</sup>, Miss Wobbie van den Hurk<sup>2</sup>

<sup>1</sup>Mindmore, Stockholm, Sweden. <sup>2</sup>Linköping University, Stockholm, Sweden

### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

### **Abstract**

The landscape of cognitive assessment is undergoing a digital revolution, and one of the players in this transformation is Mindmore. Cognitive assessments plays a pivotal role in the care of many patient groups; however, the traditional manual and resource-intensive testing methods have limited its widespread adoption.

Mindmore embodies the potential to democratize cognitive testing, making it accessible across diverse healthcare settings: digital testing when possible, physical testing when needed. This presentation critically explores the broader implications of digital cognitive testing, with Mindmore serving as a case study. Sara Wallén, who presents from Mindmore, is one of two authors and creators of the guiding checklist for implementing digital testing in Swedish healthcare clinics.

One of the primary opportunities offered by digital cognitive testing is the potential for greater accessibility. It eliminates geographical barriers and reduces the resource burden, allowing a wider range of patient groups to benefit from cognitive assessment.

Moreover, the speed at which Mindmore has gained recognition in national guidelines reflects the agility of digital solutions in the healthcare ecosystem. It challenges the traditional timelines for implementing innovations, reducing the gap between research and real-world application.

However, this digital frontier also presents limitations that warrant careful consideration. Concerns such as data privacy, security, and the digital divide must be addressed to ensure equitable access. The reliance on technology raises questions about the accuracy and reliability of digital cognitive testing compared to traditional methods.

In conclusion, Mindmore serves as a beacon in the ongoing digital transformation of cognitive assessment. It offers exciting opportunities for greater accessibility and accelerated implementation but also raises important questions about privacy, security, and accuracy. This presentation aims to foster a critical discussion on the prospects and challenges of digital cognitive testing, shaping the future of healthcare in the realm of brain health.



### Time for Dementia: Engaging people with dementia and their carers in developing EDI principles

**Dr Stephanie Daley**<sup>1</sup>, Dr Molly Hebditch<sup>2</sup>, Mrs Yvonne Feeney<sup>2</sup>, Mr Thabrez Khan<sup>3</sup>, Prof Sube Banerjee<sup>4</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Aim:** The Time for Dementia (TFD) is an educational programme for healthcare students to learn from 'experts by experience' through longitudinal contact with a family affected by dementia. In 2021, as a result of a student complaint about racism, expectations of inclusivity, diversity and inclusion (EDI) were examined and an anti-discriminatory practice plan for TFD was developed. One of the proposed outputs of this plan was the creation of a communique to outline the expectations on EDI for participant families and students in TFD.

**Methods:** The iterative development of the final communique included; The formation of a working group including student inclusivity representatives and TFD families to develop the communique, and development of a draft set of 'inclusivity principles' Pilot of the draft principles with 15 TFD families and subsequent amendment. Circulation of EDI principles to all families and students taking part in TFD from July 2022 onwards.

A qualitative research study on the reception of these principles by TFD families (n=14).

**Results:** This poster will present the communique, the results of the thematic analysis on its reception, and key reflections on its development.

**Conclusions:** Universities have a duty of care to ensure that healthcare students do not experience discrimination during their training. Educational programmes which include people with dementia and their carers need special consideration. This work is ongoing, and we hope that this offers confidence by other dementia educators to engage with these issues.



# Adaptation of experts by experience to online settings: A qualitative exploration of online delivery of Time for Dementia.

Dr Molly Hebditch<sup>1</sup>, Dr Stephanie Daley<sup>1</sup>, Ms Yvonne Feeney<sup>1</sup>, Prof Sube Banerjee<sup>2</sup>

<sup>1</sup>Brighton and Sussex Medical School, Sussex, United Kingdom. <sup>2</sup>University of Plymouth, Plymouth, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Aim:** to investigate the experiences of students on online dementia education with 'experts by experience.'

Time for Dementia, a longitudinal dementia education programme with people with dementia and carers (experts by experience), was adapted in 2020 to an online format in response to COVID-19 pandemic. This was an unanticipated change in the programme delivery which outcomes is not yet understood. Online delivery has shown to be a feasible option for some educational programmes, and resources for curriculum need to be considered as well as desired student outcomes. However, its impact and acceptability to students is an important factor. This study aims to understand the student perceptions of virtual visits.

**Methods:** Participants were undergraduate healthcare students that had taken part in TFD between 2019-2023 and either received both online and in-person (hybrid) formats or online only format. Students completed a satisfaction survey that included open-text questions about their experiences. A content analysis (n=180) was completed to understand student perceptions. This was used to inform the topic guide for a focus group (n=3) to explore this further.

**Results:** This poster will present the main findings from the content analysis (which identified unique concerns for online visits such as the role of facilitator and group dynamics) and the focus group.

**Conclusion:** These findings will have implications for online dementia education that involve 'Experts by Experience'. It will provide students views on benefits versus disadvantages, when it might be the preferred format, and can inform how online delivery can be optimised (if needed).



# **Enhancing Nutrition and Mealtime Experience for Individuals with Dementia: Strategies and Considerations**

Mr Darko Zrnic<sup>1</sup>, Ms Tracey Waldron<sup>2</sup>, Ms Kate Griffin<sup>3</sup>

<sup>1</sup>DSiDC, St. James Hospital, Dublin, Ireland. <sup>2</sup>Department of Clinical Nutrition and Dietetics, St James Hospital, Dublin, Ireland. <sup>3</sup>Speech and Language Therapy, St. James Hospital, Dublin, Ireland

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

Cognitive impairments, sensory changes, motor skill decline, and behavioural symptoms are very often contributing factors to mealtime difficulties and can lead to poor dietary intake, malnutrition, and related health complications.

Mealtime challenges are prevalent among individuals with dementia, impacting their nutritional intake, overall health, and quality of life. This presentation will explore various strategies aimed at improving their nutritional status, ensuring adequate food intake, and enhancing the overall dining environment.

Additionally, the presentation delves into the psychological and emotional aspects of mealtime, emphasising the importance of maintaining a positive and dignified dining experience.

Key strategies to address nutrition and mealtime difficulties will be presented. These strategies encompass modifications to the dining environment, such as creating a calm and familiar setting, and reducing distractions. The presentation also emphasises the significance of carer support and education, as well as the importance of involving individuals with dementia in meal-related decisions where possible.

Furthermore, it explores the role of food presentation, texture modification, and sensory stimulation in promoting successful eating experiences for individuals with dementia. The presentation underscores the need for a person-centred approach that recognises individual preferences, cultural backgrounds, and dietary restrictions.

In conclusion, I will emphasise that addressing nutrition and mealtime difficulties in individuals with dementia requires a comprehensive and tailored approach. By integrating strategies that consider both nutritional needs and the individual's cognitive and sensory abilities, it is possible to enhance mealtime experiences, promote better nutritional intake, and ultimately improve well-being.



## Research involvement, support needs, and factors affecting research participation: A survey of dementia specialist nurses

**Miss Amy Pepper**, Dr Emma Wolverson, Dr Karen Harrison-Dening Dementia UK, London, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Aims:** The aim of this study was to describe the current levels of research involvement and research mindedness in specialist dementia nurses (Admiral Nurses), as well as exploring the factors that act as barriers and facilitators to nurses engaging in research, and their support needs in relation to research.

**Methods:** A self-administered, anonymous questionnaire was distributed by email to all Admiral Nurses, containing both open and closed questions, exploring research experience and involvement, research goals, barriers and facilitators to engaging in research and support needs. Demographic details were also collected.

Frequencies and univariate analyses were calculated to examine relationships between: (i) involvement in research, qualifications and NHS banding; and (ii) current enrolment in a higher degree study, research goals, and current research involvement by level of research skill. Open-ended responses questions were collated and summarized using qualitative thematic analysis.

**Results:** The survey found a positive relationship between the highest academic qualification of the nurses and their current or previous research involvement as well as their desire to be involved in research in the future. Many of the nurses held research goals, but more support was needed to help them realise those goals. Qualitive themes included experiences on a continuum, obstacles and support needs.

**Conclusion:** Specialist dementia nurses are keen to be research active and engaged but support is needed to help them realise those ambitions. Dementia UK is using the results of this survey to develop a suite of resources to support nurses to become more research minded and increase research capacity. The findings will also be discussed in the wider context of the development of Dementia UK's first research strategy, and the implications for the engagement of specialist dementia nurses in research in the wider international context.



# A Systematic Review of the Effectiveness of Educational Interventions in Promoting Person-Centred Care in Dementia Services

Miss Chiara Carparelli<sup>1</sup>, Dr Gerard Riley<sup>1</sup>, Prof Jan Oyebode<sup>2</sup>, Dr Christopher Jones<sup>1</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Objectives:** To review evidence about the effectiveness of educational programmes in promoting the delivery of person-centred care by staff in dementia services.

**Methods:** Several databases were searched, and the methodological quality of identified studies systematically evaluated. A summary mean effect size was calculated for several types of outcome (direct knowledge, applied knowledge, attitudes, self-reported and observed working practices).

**Results:** Eighteen studies were identified. Results were mixed, with findings of no change, significant improvement, and (in attitude) significant deterioration. Effect size was modest for direct knowledge (standardized mean difference = 0.6), but small or negligible for applied knowledge (0.29) and self-reported (0.06) and observed (0.25) working practices. There was a negative effect for attitudes (-0.17).

**Conclusions:** The quality of evidence was poor. Apart from attitudes, the effect sizes are likely to be overestimates. There was little evidence that education programmes can reliably produce substantial improvements in working practices.

**Clinical implications:** Education alone is unlikely to be sufficient for establishing high standards of person-centred care in services. It needs to be supplemented by steps to ensure that staff develop skills in delivering such care in practice, and by organizational support to ensure staff have sufficient motivation, cues and opportunities for implementation.



# Supporting family carers of care home residents with advanced dementia make end of life decisions using the Comfort Care Guide e-Resource

**Dr Gillian Carter**, Dr Julie Doherty, Ms Lana Cook, Prof Kevin Brazil, Prof Christine Brown Wilson Queen's University Belfast, Belfast, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

It is common for people living with dementia to be admitted into a care home when they are in the advanced stages of dementia. When a person living with dementia loses the capacity to make a decision for themselves, care home staff must deliver care that is in the person's best interests. Ideally, decisions should be made involving those close to the person, typically a family carer. Best interest decision-making on goals of care at the end of life is complex and can become a burden for family carers and healthcare staff. Evidence suggests that staff training increases both competence and confidence in discussing end-of-life care preferences with family members. Using the Comfort Care Booklet in combination with a family care conference supports nurses in necessary discussions with family carers of residents with advanced dementia about comfort care. The e-resource: www.comfortcareguide.com (2023) was developed from a transnational study across seven countries, where researchers provided this training. This e-resource is now publicly available for care home nurses to access independently. Key components of the e-resource include using a Comfort Care Booklet to educate on end-of-life care goals; holding a family care conference; communication skills and discussing sensitive topics, and reflective practice.



# Changi General Hospital and SingHealth Community Hospitals Multi- Disciplinary Team case discussion

Dr Ching Ching Sim<sup>1</sup>, Dr Catherine Chan<sup>2</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### Abstract

There is an increased need for inpatient rehabilitation for Patients with Dementia (PWDs). Their main diagnosis for hospitalization is not dementia, instead are for other reasons such as functional decline following an acute illness or fractures.

SingHealth Community Hospitals (SCH) Dementia services is driven by a multi-disciplinary team (MDT). The Community Psychogeriatric Programme (CPGP) of Changi General Hospital Community (CGH) is a MDT service known for its strengths in dementia education and training. The partnership program between 2 sites started in 2022. The aim of the program is to conduct case-based discussions with a focus on Patient Centered Care (PCC). The discussion was held virtually to increase accessibility to the discussion and to maximize participation rate. Case discussions were based on the Enriched Model, led primarily by doctors/nurses. Discussions were robust with high participation rates from the different sites.

Till date, we have conducted 4 case-based discussions and involved more than 50 participants in total. The MDT was made up of doctors, nurses, advanced practice nurses, physiotherapists, occupational therapists, social workers, speech therapist, dietitians and psychologists. The input by psychologists was especially valuable to the SCH MDT. Some of the qualitative feedback from the SCH participants include the following: "The discussion evolved and other than the Why, we went into the How, which helped in case management in SCH."; "It is an inspiring way to learn from each other and get fresh new perspectives from various partners especially in a climate of challenges in caring for PWDs in a perpetual of infrastructure and social challenges".

Moving forward, the program seeks to let other allied health MDT members lead the discussion, so it can be conducted from a less medical-focused perspective. Providing onsite training is also being explored.



# Collaborating to co-produce educational content to champion dementia care in acute care settings: Lessons learned

**Dr Shelley Peacock**<sup>1</sup>, Dr Anna Jack-Waugh<sup>2</sup>, Dr Rhoda MacRae<sup>3</sup>, Ms Mary Harrison<sup>1</sup>, Ms Sarah Nickel<sup>1</sup>, Dr Jill Bally<sup>1</sup>, Dr Allison Cammer<sup>1</sup>, Dr Kristen Haase<sup>4</sup>, Dr Lillian Hung<sup>4</sup>, Dr Hannah O'Rourke<sup>5</sup>, Dr Noelle Rohatinsky<sup>1</sup>, Dr Genevieve Thompson<sup>6</sup>, Dr Megan O'Connell<sup>1</sup>

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### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

Enhancing care to benefit people with dementia and their family carers requires both global and local initiatives. Acute care settings often lack care approaches tailored to persons with dementia, as a result, visits are unnecessarily distressing. The purpose of this presentation is to share how we adapted a successful Scottish initiative (known as the Scottish National Dementia Champions Programme) to our local Canadian context with the ultimate aim to 'champion' dementia care provided by healthcare professionals in acute care settings. To guide our co-production, we are employing Hawkins et al.'s threephase framework: (1) evidence review and stakeholder consultation, (2) co-production of intervention content, and (3) prototyping. After phase one was completed (in February 2020) we embarked on phase two and learned several key lessons from the co-production of the program content. These include the importance of (a) partnering with those with lived experience to infuse their voices in all aspects of the program; (b) learning and benefitting from our Scottish colleagues' rich experiences; (c) capitalizing on long-standing Pan-Canadian relationships and launching new ones; (d) meeting virtually, on a consistent basis over 12 months, with established agendas and precise minute-taking; and (e) building consensus on what and how to prioritize program content and resources to align with the Canadian Charter of Rights for People with Dementia, within the foundation of person-/family-centred care. The results of our work in phase two enable us to proceed with phase three to pilot the co-produced program's content and resources in the Canadian province of Saskatchewan.



# Feasibility and acceptability of nidus-professional, a training and support intervention for homecare workers caring for clients living with dementia: A cluster- randomised feasibility trial

Prof Claudia Cooper<sup>1</sup>, Ms Sedighen Zabini<sup>1</sup>, Ms Amirah Akhtar<sup>2</sup>, Ms Teresa Lee<sup>3</sup>, Mr Abdinasir Isaaq<sup>3</sup>, Ms Marie Le Novere<sup>3</sup>, Dr Katherine Lord<sup>4</sup>, Dr Penny Rapaport<sup>3</sup>, Dr Sara Banks<sup>1</sup>, Dr Sandra Duggan<sup>1</sup>, Mrs Margaret Ogden<sup>1</sup>, Prof Kate Walters<sup>3</sup>, Dr Ian Lang<sup>5</sup>, Dr Vasiliki Orgeta<sup>3</sup>, Prof Kenneth Rockwood<sup>6</sup>, Prof Laurie T Butler<sup>7</sup>, Prof Jill Manthorpe<sup>8</sup>, Prof Briony Dow<sup>9</sup>, Prof Juanita Hoe<sup>10</sup>, Prof Rachael Hunter<sup>3</sup>, Prof Sube Banerjee<sup>11</sup>, Ms Jessica Budjett<sup>1</sup>, **Ms Larisa Duffy**<sup>3</sup>

<sup>1</sup>QMUL, London, United Kingdom. <sup>2</sup>University of Bradford, London, United Kingdom. <sup>3</sup>UCL, London, United Kingdom. <sup>4</sup>University of Bradford, Bradford, United Kingdom. <sup>5</sup>University of Exeter, Exeter, United Kingdom. <sup>6</sup>Dalhousie University, Halifax, Canada. <sup>7</sup>Anglia Ruskin University, Cambridge, United Kingdom. <sup>8</sup>KCL, London, United Kingdom. <sup>9</sup>National Ageing Research Institute, Melbourne, Austria. <sup>10</sup>University of West London, London, United Kingdom. <sup>11</sup>University of Plymouth, Plymouth, United Kingdom

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

**Aims**. Homecare workers (HCWs) support many people with dementia. We developed manualised training and support for HCWs (NIDUS-Professional). Our aims were to assess (i) acceptability when delivered by non-clinical facilitators (ii) feasibility of outcome completion and (iii) costs for a future trial.

**Methods.** This cluster-randomised (2:1) single-blind, feasibility trial involved English homecare agencies. Intervention arm agency staff were offered group videocall sessions: six over three months, then monthly for three months. Carers and clients (dyads) were offered a 6-8 session complementary, individual intervention (NIDUS-Family). We collected potential future trial measures as secondary outcomes remotely at baseline and six months: HCW Work-related Strain Inventory (WRSI), Sense of Competence (SoC); client proxy-rated Quality of Life (QOL), Disability Assessment for Dementia scale (DAD), Neuropsychiatric Inventory (NPI), and Home Care Satisfaction (HCS).

**Results.** From December 2021 - September 2022, we met agency (4 intervention, 2 control) and HCWs (n=62) recruitment targets and recruited 16 family carers and 16/60 planned clients. We met a priori progression criteria for adherence (≥4/6 sessions: 29/44: 65.9%); HCW or carer proxy-outcome completion (15/16 (93.8% [95% confidence interval (CI): 69.8, 99.8]); and proceeding with adaptation for HCWs outcome completion (46/63 (73.0% [CI: 60.3, 83.4]). Delivery of NIDUS-Professional costs £6,423 (£137 per eligible client). WRSI scores decreased and SoC increased in both groups. For intervention arm proxy-rated outcomes, QOL rated by carers increased, and by HCW was unchanged; carer and HCW-rated NPI decreased; DAD decreased (greater disability); HCS was unchanged at follow-up.

**Conclusion**. We will consider using aggregated, agency-level proxy-rated client outcomes, including neuropsychiatric symptoms, in a future trial. To increase agency buy-in we will also consider paying HCW research champions' time, face-to-face collection of data and engaging agency management in intervention. NIDUS-Professional may, if effectiveness is demonstrated, provide a credible option for homecare agencies to deliver training and support



### Measuring Person-Centered Care Behavior of Professional Care Partners

Ms Melora Jackson

Second Wind Dreams, Roswell, USA

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### Abstract

In the United States, several states have implemented a person-centered dementia care training programs through project grants. The results of this program show that there is an increase in empathic person-centered care along with clear statements of competency. Design initiatives will be covered along with specific strategies that can be applied in all settings. The nursing homes in many states that have implemented this program have already set a trend for the development of person-centered care initiatives, dementia competency, ongoing training, and sustainability. Ways to track staff competence, measurement of intangibles like empathy and resident/patient to staff relationships, and how the results of these nursing home projects utilizing the training interventions and contingent assessment tools meet guidelines will be discussed. These training interventions and measurement tool can be used in a variety of care environments. The importance of and practice of empathic person-centered dementia care, ways to make person-centered care concepts tangible through experiential learning, and measuring the impact of that experiential learning with observational assessments will be highlighted.



## Tackling sex and gender inequalities in effective treatment and support: findings from a narrative review study

**Ms Elisa Aguzzoli**<sup>1</sup>, Dr Magdalena Walbaum<sup>1</sup>, Prof Martin Knapp<sup>1</sup>, Ms Anushka Madhukar<sup>1</sup>, Dr Eva Cyhlarova<sup>1</sup>, Dr Laura Castro-Aldrete<sup>2</sup>, Dr Antonella Santuccione Chadha<sup>2,3</sup>

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### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

**Aims/Background:** Women have a greater risk of developing dementia, with almost twofold increased risk of Alzheimer's disease (AD) compared to men. Women experience faster cognitive decline. Women are typically primary caregivers for people with dementia. Factors potentially contributing to sex/gender differences in AD progression relate to differences in the AD patient journey, including time of diagnosis and treatment initiation, treatment type, and individual characteristics such as hormonal changes, lifestyle, and other health conditions. Effective pharmacological and psychosocial interventions can slow down disease progression and reduce sex/gender gaps.

**Methods:** Narrative review of trials looking at the effectiveness of interventions in slowing AD progression and supporting carers. Exploration of potential impacts of interventions in reducing sex/gender inequalities.

**Results:** Published data reporting sex/gender disaggregated information is very limited. Current evidence on effectiveness of drug treatments, both symptomatic and disease-modifying, in slowing progression of AD in women is inconclusive. Women are less likely to participate in AD clinical trials, which results in pre-selection bias based on socio-demographic characteristics, limiting representativeness and generalisability of results. Timing of diagnosis may have sex/gender differences. Cognitive Stimulation Therapy (CST) improves cognition and quality of life, particularly for women. The cost-effectiveness of CST is greater when delivered in combination with acetylcholinesterase inhibitors. Carer support programmes are equally effective for men and women. Scaling-up CST for people with dementia as well as promoting effective support programmes for carers would reduce sex/gender inequalities in AD.

**Conclusions:** Sex/gender differences in effectiveness of treatments (pharmacological, psychosocial) are often overlooked. Cost-effective interventions have the potential to reduce these inequalities if made more widely available. Since most carers are women, scaling up cost-effective carer support would also reduce inequalities. Research, practice, and policy should focus more on addressing sex/gender disparities in health and social care.





### Knowledge of dementia and personhood among professional dementia care staff in the United Arab Emirates

Ms Seada Kassie<sup>1</sup>, Prof Arlene Astell<sup>2,1,3,4</sup>

<sup>1</sup>University of Reading, Reading, United Kingdom. <sup>2</sup>Northumbria University, Newcastle-upon-Tyne, United Kingdom. <sup>3</sup>University of Toronto, Toronto, Canada. <sup>4</sup>University Health Network, Toronto, Canada

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

**Introduction:** The United Arab Emirates, consistent with the global ageing trend, is predicted to see a rise in Emiratees aged over 60 from 5.1% in 2017 to 19% in 2050. With an ageing population the numbers living with dementia and other conditions of aging is also predicted to rise. Currently there are only a handful of centres providing specialized care for dementia, and little is known about their models and training in dementia care, for example use of person-centred approaches.

**Objective:** To assess knowledge of dementia and the concept of personhood in dementia care in the United Arab Emirates.

**Method:** In this cross-sectional study, 49 participants (F= 27; mean age 45 years [SD=8.79]) were recruited including physicians, registered nurses, assistant nurses, and physiotherapists. Participants completed the Dementia Knowledge Assessment Scale (DKAS; Annear et al., 2017) and the Personhood in Dementia Questionnaire (PDQ; Hunter et al., 2013) via an online platform, along with demographic question about their age, sex, duration of employment, and position at the care facility.

**Results:** Overall scores on the DKAS suggested that knowledge of dementia was above average whereas average scores on the PDQ indicated good understanding of personhood. However, further analysis of responses to specific items on both measures identified high levels of endorsement of incorrect items and areas of major inconsistencies and difference between respondents.

**Conclusions:** The findings indicate gaps in knowledge among dementia care staff in the United Arab Emirates regarding dementia as a neurocognitive disorder and the personhood of people living with dementia. The results can be used to inform development of person-centred training to enhance dementia care in Dubai and increase capacity to address the growing numbers of people living with dementia.



### Translating knowledge into care to enhance sensory-cognitive health of people in long-term care facilities in Ireland

Mr JP Connelly<sup>1</sup>, Miss Erin Boland<sup>1</sup>, Prof Iracema Leroi<sup>2</sup>

<sup>1</sup>Trinity College Dublin, Dublin, Ireland. <sup>2</sup>Global Brain Health Institute, Trinity College Dublin, Dublin, Ireland.

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### Abstract

**Aims:** Up to 90% of long-term care facility (LTCF) residents have significant hearing and/or vision loss, usually undetected or uncorrected. Also, sensory environments (i.e., noise, lighting levels) in LTCFs are often difficult, contributing to low quality of life. Training staff to address sensory-health issues is critical to address this. The sensory support intervention for long term care (SSI-LTC) is part of the Sense-Cog Residential Care pilot study to test the feasibility of a sensory support intervention for residents with dementia (RwD) in LTCFs. This reports the translation of the SSI-LTC into promotional-educational resources for LTCF healthcare professionals.

**Methods:** Material from the staff training component of the SSI-LTC - consisting of a general staff training event and more specialised 'sensory champion' training - was used to inform the development of two multi-media outputs to (1) raise awareness of sensory cognitive health in RwD and (2) train long term care facility (LTCF) staff to conduct the SSI-RC.

**Results:** Two multi-media outputs were produced: a short, online, promotional-educational awareness raising video about sensory health for widespread use in Irish LTCFs, relevant third sector organisations and the interested public, and two online extended digital modules to train (i) LTCF staff in dementia, sensory-cognitive health, and strategies to improve communication and troubleshoot sensory device problems, and (ii) Sensory Champions in delivering the SSI-LTC.

**Conclusion:** These professionally developed resources convert our research into practice to improve sensory-cognitive health in LTCF RwD in Ireland.



## Analysis of qualitative measures of care in residents of 7 Nursing Home in Sassuolo after training and geriatric support

Mrs Barbara Manni<sup>1,2</sup>, Mrs Rossella DiFeo<sup>3</sup>, Prof Andrea Fabbo<sup>4</sup>, **Mr Allesandro Lanzoni**<sup>5</sup>

<sup>1</sup>Cognitive Disorders and Dementia unit, Modena, Italy. <sup>2</sup>Primary care, Sassuolo, Italy. <sup>3</sup>Primary Care, Sassuolo, Italy. <sup>4</sup>Primary Care, Modena, Italy. <sup>5</sup>Local Health Authority Modena, Strada Martiniana, Italy.

### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

### **Abstract**

The aging of the population and the presence of many frail and multimorbidity olders has become a serious problem to the society worldwide. Dementia as comorbidity, in particular if associated with psychiatrist symptoms is the most challenge for carers and professionals in Nursing home. Systematic training programs for NH's staff could improve the quality of life of residents. The Person Center Care (PCC) approach seems to be associated to positive outcome in residents with dementia. In literature, the pharmacology review using STOPP criteria for potentially unappropriated medications, demonstrated an improvement in clinical outcomes in multi-morbid people. In our observational study we want to document the clinical outcomes trend of an elderly population resident in 7 NH in Sassuolo after training for staff.

**Methods:**50 staff workers attended the course. The training consisted on 3 residential, 2 field training and a final staff project work, in the meantime a Geriatrician was available for consultations in the facilities. The main topic of the course were knowledge about dementia and PCC approach, START/STOPP criteria. We collected clinical data for 426 veteran residents and matched datas pre (T0) and post training (T1 after 6 months and T2 after one years). The data collected were: use of antipsychotic drugs, physical restraints, falls, bedsores, deaths and hospitalized.

**Results:**4/7NH reduced antipsychotic drugs after 6 month (T1) and 5/7 NH after one year (T2), 5/7 NH reduced physical restraints in T1 and 6/7 NH in T2, while falls increased in the NH where restraints reduced. Most of falls did not caused fractures. 6/7 NH reduced bedsore in T1 and T2. There were not differences in deaths but reduced hospitalizations

**Conclusion:** A systematic training and a specialist support can improve the staff's care work and quality of care, at the same time leads positive outcome in residents



### P19-001

### Practice content of end-of-life care through collaboration between nursing and caregiving staff in integrated facilities for medical and long-term care

Prof Sachiko Hara, Mrs Maki Kato

Shimane University, Izumo, Japan

### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Aim:** Integrated facilities for medical and long-term care in Japan provide long-term medical treatment and living to elderly people requiring long-term care, including those with dementia and cognitive decline, and to support the end-of-life care of the users is one of the important roles of the facilities. The purpose of this study is to extract specific practice content of end-of-life care through collaboration between nursing and caregiving staff in such integrated facilities.

**Methods:** The study subjects were five care staff members from three integrated facilities for medical and long-term care, and data were collected through focus group interviews. The main discussion topic was "What kind of end-of-life care is practiced specifically through collaboration between nursing and caregiving staff?"

**Results:** As specific practice content of end-of-life care through collaboration between nursing and caregiving staff, the following was extracted:

- The same nursing and/or caregiving staff members shall continue the care until the end
- See the daily conditions of users together with nursing and caregiving staff
- Nursing and caregiving staff shall work together to provide bathing services as much as possible
- Both nursing and caregiving staff shall be aware of small changes in daily conditions and medical conditions of users
- Fulfill the wishes of users who cannot have a regular life because of hospitalization/admission>, and 5 other contents.

**Conclusion:** When cooperation/collaboration between nursing and caregiving staff has matured and each staff member can work subjectively, they will be able to contribute to the improvement of the quality of end-of-life care.



### P19-002

# "Mum had a right for her voice to be heard, but it wasn't": Calling for better palliative and end-of-life care for people affected by dementia

### **Dr Lesley E Williamson**

King's College London, London, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Aim:** The quality of end-of-life care for people with dementia is variable. We aimed to produce a policy brief summarising the latest evidence to inform recommendations towards improving care for people with dementia who are approaching the end of their lives.

**Methods:** We sourced primary and secondary studies of qualitative, quantitative and mixed methods design. We summarised findings to inform recommendations for change.

**Results:** Informed by synthesised findings, we developed eight recommendations, categorised into fours calls to action:

- Prioritise dementia as a life-limiting condition: It is recommended that clinical training and public health messaging focus on dementia as a life-limiting condition to increase equity of access to care.
- Ensure equitable access to integrated palliative dementia care: It is recommended that an integrated palliative care approach is adopted, and that Integrated Care Boards consider dementia in fulfilling their statutory duty to respond to local palliative care needs.
- Optimise investment in community and primary care closer to home: It is recommended that primary, community and urgent care services are locally integrated through greater investment and joint workforce planning.
- Invest in palliative dementia care research: It is recommended that routinely collected data is expanded and dementia care research receives greater priority and investment.

**Conclusions:** Our recommendations aim to ensure that people with dementia approaching the end of life receive equitable care. Next steps towards better palliative and end-of-life care will rely on greater investment, strong leadership, and strong collaboration between people affected by dementia, researchers, clinicians, commissioners and Government.



### P19-003

### Comparing medical service utilization and mortality between dementia and non-dementia residents with advance directives in nursing homes

#### **Prof Hsiu-Hsin Tsai**

333 Wen-Hwa 1st Road, Tao-Yuan, Taiwan

### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Aim:** Whether do-not-resuscitate directive influences the medical service utilization in dementia and non-dementia residents in nursing homes is unknown. This study aimed to compare the difference in medical service utilization and mortality between dementia and non-dementia residents with do-not-resuscitate directive in nursing homes.

**Methods:** This study involved a secondary analysis of data obtained from a large three-year longitudinal study. Medical service utilization (nasogastric intubation, Foley, medicines, and one-year emergency room transfer times) and one-year mortality were compared among four groups (with and without do-not-resuscitate; with and without dementia). Associations between signing a do-not-resuscitate directive and mortality were examined using Cox proportional hazard regression models.

**Results:** There was no significant difference in the prevalence of DNR directives between dementia (10.14 %) and non-dementia group (13.60 %) (X2=0.63, p=0.43). Residents with dementia but without do-not-resuscitate (2.30  $\pm$  3.48) group was the most often group transferred to the emergency room among all the four groups (p<0.001). Those who were with DNR tended to have a higher rate of nasogastric tube intubation, with the percentages for the dementia and without dementia groups being 58.3 % and 56.6 %, respectively. Dementia with do-not-resuscitate group (hazard ratio, 4.13) and dementia without do-not-resuscitate group (hazard ratio, 2.89) were at an increased risk of mortality.

**Conclusion:** Do-not-resuscitate directive doesn't decrease the medical service utilization, but dementia diagnostic increase emergency room transfer. Education related to end-of-life care of dementia residents is suggested in the institution.



#### P19-004

## Advance care planning support by dementia support workers: what works, for whom and in what circumstances.

Dr Tomasina M Oh¹, Ms Hannah Jones¹, Dr Thomas Thompson¹, Ms Lorna Smith¹, Ms Hannah Shafi², Ms Noor Butt², Ms Tanya Lee², Dr Sarah Griffiths³, Dr Lauren Weston¹, Dr Basharat Hussain¹, Dr Sarah Morgan-Trimmer⁴, Dr Cath Quinn¹, Dr Paul Clarkson², Dr Michael Clark⁵, Prof Richard Byng¹, **Dr Hannah Wheat**¹

<sup>1</sup>University of Plymouth, Plymouth, United Kingdom. <sup>2</sup>University of Manchester, Manchester, United Kingdom. <sup>3</sup>UCL, London, United Kingdom. <sup>4</sup>University of Exeter, Exeter, United Kingdom. <sup>5</sup>LSE, London, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

Advance care planning (ACP) occurs when a person with a serious chronic condition considers and shares (sometimes through documentation) their values, wishes, and preferences for future care. Many people with dementia are not encouraged to engage in ACP, despite awareness that as dementia progresses, people will be less able to consider and communicate future wishes. This is concerning as ACP can provide several benefits, such as better experiences of care; reduced anxiety about death; increased feelings of autonomy and control and reduced depression for carers. Two frequently reported barriers are 1) people with dementia and carers find it difficult to find the right time for the discussion and 2) they don't receive sufficient information or support from professionals. Such findings have led some to recommend that ACP should be provided by experienced dementia case managers, who can be ready to support ACP discussions throughout the dementia trajectory. Throughout the UK dementia support workers (DSWs) have, to varying degrees, been given the role of case manager, yet no studies have examined their delivery of ACP support. The Dementia PersonAlised Care Team (D-PACT) study has used a realist approach to develop and (currently) evaluate a primary care based DSW role. A core component of the D-PACT DSW role is to support future planning - including ACP. Part of the ongoing analysis of mixed-qualitative data from both DSWs (n= 8) and people supported (n = 127 people with dementia, 121 carers) involves testing, elaborating and refining a set of programme theory statements relating to when, how and for whom DSW-led ACP discussions worked (in terms of whether preferences and wishes about future care were shared). This presentation will share the results of this analysis and provide evidencebased guidance on whether and how a case manager approach to ACP within dementia care works.



## P19-005

## Predicting outcomes for people living with dementia requiring psychiatric inpatient care in the Cambridgeshire

Ms Oriane Marguet<sup>1</sup>, Dr Shanquan Chen<sup>2</sup>, Dr Ben Underwood<sup>1,3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

Dementia represents a major health challenge. People living with dementia (PLWD) can develop behavioural and psychological symptoms requiring them to be cared for in specialist dementia mental health wards. However, there has been little research on their needs, their mortality or discharge outcomes, although it is known that PLWD requiring inpatient care wish to be discharged home and not to have any further readmission to a psychiatric ward. The work presented here explores whether their outcomes can be predicted at their time of admission to the ward. If it is possible, it could allow targeted interventions to optimize discharge outcomes.

We conducted a retrospective analysis of 576 PLWD admitted to specialist mental health dementia wards using the electronic patient record from the Cambridgeshire and Peterborough NHS Foundation Trust (United Kingdom). We performed a Kaplan-Meier survival analysis to investigate their mortality. Demographic and clinical variables were then used to build machine learning models predictive of specific outcomes (passing away within a year of admission or not; successful or unsuccessful discharge).

We found that the median survival length in our cohort is 680 days post-admission. We could not build accurate models to predict who is at risk to pass away within a year of admission. However, we found sufficient differences between PLWD experiencing other discharge outcomes to build a logistic regression model predicting their likelihood of successful discharge, which we define as going home with no future readmission.

The high rate of mortality on wards indicates an enhanced need for palliative care, but any intervention cannot be targeted using the information we examined. However, routinely collected data can be used to build machine learning models with a clinical utility to predict who is likely to experience unsuccessful discharge, opening possibilities for the development of tailored interventions aimed at maximizing discharge home.



## P19-006

# The Family Members' Perspective on Advance Care Planning & Making End-of-Life Treatment Decisions for Their Severe Dementia Elders in a Nursing Home

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#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

**Background:** & **Aims:** In Taiwan, the Patient Autonomy Act was legislated in 2015, formally implemented, and published on January 6, 2019, becoming the first in Asia. The five specific clinical conditions include severe dementia, emphasizing that competent adults can make end-of-life medical decisions in advance. Until now, the signature of Advanced Directive did not increase stably.

**Methods:** In 2019, we completed a descriptive quantitative and qualitative study to investigate 23 family members' perspectives on the issues of the Advance Care Planning use for severe dementia in a Nursing Home in Taipei. The purposive sampling with structured intentions-based rankings and open-ended questions was for data collection.

**Results:** Only six family members had heard of the Advance directives. Everyone rejected the extracorporeal membrane oxygenation (ECMO); only one required endotracheal intubation; one accepted hemodialysis; two required cardiopulmonary resuscitation(CPR); and five required respirators. Within a 10-level scale, the average score for acceptance of intravenous (IV) water or nutritional items was 5.4, the nasogastric tube was 4, and the average score for gastrostomy was 1.1.

**Discussion:** Family members may consider intravenous infusion and nasogastric tubing less invasive, matching with the Chinese norm of filial piety and custom about rejecting the feeling of hunger to death. They refuse gastrostomy in order to maintain an integrative body image in daily life. Most dementia family members appeared to influence medical treatment decisions strongly but not confidently with what the dementia family members precisely like.

**Conclusion:** The dementia family must understand the members' preferences, coincidence, and the importance of executing patients' autonomy. Most dementia elders cannot express their treatment preferences due to the unknown illness truth and the death taboo in Asian culture. Therefore, designing a culturally sensitive and appropriate education for facilitating early truth-telling and ACP for dementia families in Taiwan is crucial for palliative care.



#### P20-001

# Nursing Excellence in the Clinical Practice of Nurses in General Hospitals A Comparison of Hospitals with and without Certified Nurses in Dementia Nursing

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Nagano College of Nursing, Komagane, Japan

#### **Topic**

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

#### **Abstract**

**Purpose:** The purpose of this study was to compare the excellence of nursing practices of nurses in general hospitals with certified nurses in dementia nursing (DCN) (Group with DCN) and those without (Group without DCN).

**Method:** The questionnaire consisted of questions about the length of working as a nurse, assigned ward, the size of the hospital, and the presence or absence of certified nurses in dementia nursing, and items from the Nursing Excellence Scale in Clinical Practice. This study was conducted with the approval of the Ethics Committee of the Nagano College of Nursing (No.2022-29).

**Results:** A total of 5,000 questionnaires were sent to 250 general hospitals randomly sampled from the Japan Hospital Association Directory together with a letter asking the nursing directors of each hospital to distribute the questionnaires to 20 nurses. Responses were collected from 1509 (30.2%) nurses, and of these 1352 (89.6%) were determined to be valid for analysis. There was no significant difference in the length of working as a nurse in the Group with DCN (n = 650) and the Group without DCN (n = 589) (p<0.05). The total score of the Nursing excellence scale in Clinical Practice of the Group with DCN (127.0  $\pm$  15.4) was significantly higher than in the Group without DCN (123.6  $\pm$  16.4)(p<0.05).

**Conclusion:** The presence of nurses with a high degree of nursing expertise may be related to the excellence of nursing practices of individual nurses. This suggests the necessity of further investigation.



## P20-002

## Enhancing Spatial Orientation for People Living with Dementia in the Urban Environment: An Evaluation-Study of the Wayfinding Infrastructure

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Institute of Public Health and Nursing Research, University of Bremen, Bremen, Germany

#### **Topic**

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

#### **Abstract**

Recent studies point to the importance of the built environment for the cognitive and social health of community-dwelling people living with dementia (PlwD). One key aspect is wayfinding infrastructure, especially in urban areas. However, there are currently no clear indicators of wayfinding infrastructure or standardized assessment instruments. Here, we provide such an instrument with the potential for online digital assessment.

Based on an umbrella review and further research in the German DenHB study, we first developed a questionnaire to assess relevant local wayfinding structures in seven different thematic blocks: 1.) general streetscape, 2.) complexity of the public traffic area, 3.) pedestrian and cycling infrastructure, 4.) signage, 5.) buildings, 6.) practical, natural and distinctive design elements, and 7.) public transportation.

Second, we conducted a cross-sectional validation study in the urban area of Bremen, Germany using Apple Maps Street View (2022) with a 360-degree viewing angle at approximately 3,000 randomly selected geo coordinates within urban districts with a high proportion of older residents (>65 years). Third, the thematic questionnaire blocks of the cross-sectional validation study will be weighted regarding the importance of orientation with PlwD and/or their relatives.

The results document supportive as well as inhibiting wayfinding structures from the perspective of people living with dementia and can also form a basis for a later automated digital evaluation of wayfinding structures. Hence, providing easy-to-obtain new insights helps to support the development of actions to promote the dementia-friendliness of urban living structures.



#### P21-002

## Education and support measures for care workers with multicultural Background:s to practice dementia care in Japan

#### Mrs Yayoi Shimizu

Kobe Women's University, Kobe, Japan

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Importance of cultural context training for carers/provider

#### **Abstract**

**Aim:** The number of migrant care workers is increasing in Japan. Although they have begun to be accepted under various residency statuses, such as "nursing care," "technical intern training" and "specified skilled worker," the level of Japanese language and professional education required varies. This presentation aims to examine the challenges that care workers with multi-cultural background and their managers face in providing dementia care.

**Method:** A qualitative survey was conducted with migrant care workers and their managers at elderly care facilities in Japan. The data collection period was 2022-2023. Data were collected using an interview guide and semi-structured interviews were conducted with care workers with multi-cultural backgroundand their managers about their working environment, professional education and the content of dementia care.

**Results:** Data were obtained from a total of 28 interviewees (17 care workers and 11 managers) from 9 facilities. First, regarding education, there was a mix of those who obtained 3 years of specialized education and those who worked with only 6 months of education. The level of Japanese also varies from N2 to N4, and some of them are working without sufficient language ability, which is essential for dementia care.

The quality and quantity of education and on-the-job training varied greatly from facility to facility, even for the same technical intern trainees.

The analysis focused on "presenting options based on life history" and "responding individually," which are important for dementia care, but only half of the care workers mentioned such responses.

**Conclusion:** Specialized education is not mandatory for migrant care workers in Japan. In order to provide dementia care, it is necessary to provide these care workers with sufficient language education and specialized training, and to establish a public system to accept them at facilities.



## P22-001

## Ageing migrants: a multicultural approach to dementia diagnosis and treatment

**Mr Luca Croci** 

Colisée Italia, Milano, Italy

#### **Topic**

Dementia diagnosis, treatment, care and support: Migration, care and dementia

#### **Abstract**

The United Nations reports that the number of migrants over 60 in Europe will increase from almost 9 million in 1990 to 19 million in 2020 . According to Immidem, this population has about 500,000 cases of dementia and 6-700,000 cases of mild cognitive disorders . A survey conducted in Italy at the Centres for Cognitive Disorders and Dementia showed that, in 2019, 4527 migrants were referred to 343 centres and 2040 underwent neuropsychological assessment, with an upward trend registered in the last five years in more than a third of the monitored centres .

In the population with a history of migration, a diagnostic delay of dementia can be observed, which is probably attributable to social isolation, economic precariousness, cultural representation of dementia, fear of not having one's cultural or religious specificities respected, as well as a major difficulty in performing cognitive tests due to partial or total language barriers. There is a pressing need in the field for cultural mediators and interpreters, staff with a migration background, translated information materials and cross-cultural neurocognitive tests that take into account the specificities of the patient. While only nine out of the 32 National Dementia Plans on the ADI website mention migrants and/or ethnic minorities, it seems essential now to adopt ambitious health policies everywhere that, through the acquisition of new cultural competences, manage to guarantee the right to health for all and protect the specific needs of each individual.



#### P22-002

## Yaad - memory of home; a participatory project exploring memory, family care and technology with South Asian community in England

Dr Neil Hedley Chadborn<sup>1,2</sup>, Mrs Saira Lloyd<sup>1</sup>, Prof Martin Orrell<sup>1,2,3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Migration, care and dementia

#### **Abstract**

**Background:** Demographic ageing is an acute problem for migrant communities as the first-generation reaches old age. The second generation may feel conflicted by expectations of employment as well as traditional family care. Stigma about professional care means that services must be sensitive and culturally appropriate. Reminiscence therapy requires complex adaptation because of the complexity of memories of place. Traumatic memories of migration and racism may have been hidden, adding to intergenerational divide. Younger generations have digital skills that can access archives and communications with relatives. We aimed to listen to views about memories and how technologies could be used to share photos, music and text.

**Method:** This participatory project aimed to build trust and co-design future research. We spoke with carers in South Asian communities, attended community groups and held a stall at a festival. At workshops in three cities, we will use creative methods to share memories and discuss family care. In post-workshop interviews we will explore people's reflections.

**Findings:** Conversations with a Muslim and a Sikh carer identified high demands of caring for parents with dementia. We presented project plans to a Punjabi women's group. The key response was to focus on either practical support for carers, or creative activities for individuals with dementia, but not to combine these. We were planning inviting mixed ethnicities to workshops, but on reflection decided that multiple languages and cultures may be problematic; now we will approach existing local groups. We met three women, previous leaders of community groups, and asked them to lead creative workshops. We have fewer Muslim contacts, so we are working with a radio station with a Muslim audience. We created a radio show to raise awareness and have conversations with experts.

We have built relationships with South Asian communities, enabling codesign of future research.





## Dementia shared care- a collaboration between primary care and a tertiary institution in Singapore to right-site care of persons with dementia.

**Dr Kar Cheng Goh**, Dr Chris Tung Tsoi National University Hospital, Singpaore, Singapore

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

Singapore is a small, heavily urbanised island city-state with a rapidly ageing population, projected to have one in four Singaporeans aged 65 and above by the year 2030. A 2012 study showed one in 10 people (around 28,000) aged 60 and above live with dementia. It is projected that by year 2030, this number will increase to 80,000.

To better meet the needs of persons living with dementia (PwD) and their families, Geriatric psychiatry outReach, Assessment, Consultation and Enablement (G-Race) is a program that provides seamless care for PwD. Funded by the Ministry of Health, G-Race collaborates with Memory Clinics led by primary care polyclinics serving the western population of Singapore. This multi-disciplinary team comprises primary care doctors and registered nurses working in polyclinics, supported by psycho-geriatricians, case managers and occupational therapists from a large teaching hospital. It provides-

- 1. Assessment of cognitive and related psychiatric symptoms in community dwelling elderly.
- 2. Early diagnosis of dementia, treatment, post-diagnostic support and case management for PwD and their care partners.
- 3. Training of primary care doctors/nurses, and empowerment of PwD and their families through workshops.
- 4. Timely management of behavioral and psychological symptoms of dementia. This minimizes emergency department visits, reduces hospitalization and avoids premature institutionalization.

Weekly multidisciplinary team meetings discuss care plans for PwD which are individualized and patient-centric, with community support services arranged as appropriate.

Dementia shared care has been shown to be effective and cost effective. G-Race program helps to rightsite care of PwD in the community.



## Application progress of Chinese medicine nursing techniques in Alzheimer's Disease

**Prof Jing Jiang**, Miss Ruxia Yu, Miss Qiucheng Wang, Miss Yue Wang Beijing University of Chinese Medicine, Beijing, China

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Abstract:** Alzheimer's disease (AD), as one of most common dementia, seriously affected the health of over 65-years old people, has brought a heavy burden to the modern world. While there is still no effective therapy to revers or stop the progress of the disease. Nowadays, people are paying more focus on the care of this kind of disease. In the long-term of practice on dementia, especially on AD, Chinese medicine nursing technologies had the advantages of strong compatibility, non-invasiveness, and easy acceptance by patients and their families. Based on this, we reviewed the application of Chinese medicine nursing techniques on AD patients in an attempt to provide new methods and ideas for home care of AD patients. However, the exact role and mechanism of traditional Chinese medicine nursing technology need to be further studied in the future.



# Comparative analysis of long-term care utilization among people living with dementia, disabilities, and comorbid conditions in Taiwan

Ms Yun-Hsuan Lee<sup>1,2</sup>, Dr Chih-Yuan Lin<sup>3</sup>, Mr Po-Yen Wang<sup>3</sup>, Dr Yi-Di Lin<sup>2</sup>

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## **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Background:** Taiwan's long-term care system operates on "Pay-as-You-Go" model. This study aims to explore the service types utilized by cognitive, disabilities or both users.

**Methods:** We analyzed our hospital long-term care users from 2020 to August 2023, categorizing participants into cognitive, disability, and combined groups. Independent variables included sociodemographic, welfare status and funding source, level of disability, and case-mix score. Dependent variables comprise cumulative services usage, services classification, participation in nursing home care and medical care outreach programs, and reasons for case closures. One-way ANOVA compared the differences among three groups.

**Results:** Our study disclosed cognitive group participants (N=276), disability group (N=312), and those exhibiting both cognitive and disability group (N=116). Female (56.1%), with an average age of  $72.7\pm15.0$  years, and mainly moderate disability, case-mix score of 5.8. The majority user were general population and applied for services independently. Cognitive group were more proactive in applying for services (p=0.0168), and predominantly utilized day-care services (p=0.0047). The disability group utilized broader spectrum of home care services (p=0.0187). Furthermore, the combined group had a higher propensity to use nursing home care (p<.0001), and it was speculated that this group had a higher incidence of cases closed (p=0.0226) possibly due to transitions to institution.

**Conclusion:** Based on the study, cognitive group's preference for proactive application and day-care services and the disability group's reliance on diverse home care services Particularly, the elevated usage of nursing home care by those with comorbid conditions highlights the need for integrated care models to accommodate compounded needs.



## Improving Residents Quality of Life through Meaningful Engagement

Mrs Joanne Chalifour<sup>1,2</sup>, **Mrs Emma Martin**<sup>1,2</sup>, Dr Sheila Boamah<sup>3</sup>, Mrs Kristy McKibbon<sup>4</sup>, Mrs Janet Plastow<sup>5</sup>, Mr Noriel Santos<sup>1</sup>, Mr Ray Melvin "Jack" Syegco<sup>6</sup>, Miss Marion Tabanor<sup>7</sup>, Mr Chad Weber<sup>6</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

The Hamilton Niagara Haldimand Brant (HNHB) Behavioural Supports Ontario (BSO) Long Term Care (LTC) team (in Canada) prioritizes the application of evidence-based strategies to enhance both quality of life and quality of care for residents that they work with. The BSO team identified that meaningful moments in the day-to-day routine of residents may enhance resident's quality of life and reduce the incidences of responsive behaviours. To increase the use of meaningful engagement and close this knowledge to practice gap, the BSO team utilized the Knowledge to Practice Framework to develop an evidence-based education curriculum. The education curriculum was implemented on two Long Term Care Home (LTCH) units at St. Joseph's Villa, Hamilton, Ontario, Canada in March of 2023. The curriculum covered different types of dementia, defined what meaningful engagement is, and offered practical strategies to increase meaningful engagement. This curriculum was supplemented by the use of introductory meetings on each LTCH unit and a communication board. This Quality Improvement (QI) project provides support and the education curriculum increases staff's knowledge and comfort level practicing meaningful engagement. It may also help to improve the quality of care received and quality of life for residents in homes. Repetitions of this project should prioritize collaboration with all levels of staff in an effort to maximize staff participation. The BSO LTC team believes that increasing staff's knowledge of meaningful engagement will enable residents to live their best life in their Long Term Care Home .



# Effectiveness of Integrated Western and Traditional Chinese Medicine Case Management Model for peoples living with dementia: A Retrospective Cohort Study

Mr Po-Yen Wang<sup>1,2</sup>, Dr Chih-Yuan Lin<sup>1,3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Background:** Taiwan's Long-Term Care Policy 2.0 emphasizes the integration of care models. Our hospital integrates Western and Traditional Chinese Medicine (WTCM) for cognitive disorders care management. This study aimed to investigate the effectiveness of the integrated WTCM case management model on continuity of care (COC), medications, and long-term services utilization patterns, and long-term care facility usage outcomes of people living with dementia.

**Method:** In this retrospective cohort study, we assessed patients newly diagnosed with cognitive disorders between 2020 and August 2023 at our hospital. Participants were divided into two groups: those who received case management (case management group) and those who declined it (control group). Covariates considered were sociodemographic factors and disease severity. Dependent variables of interest comprised COC, medication, long-term care services, and facility utilization. We used chisquare tests for categorical variables and T-tests to compare group differences.

**Results:** In this study, the case management group consisted of 242 participants, while the control group had 622 participants. Two cohorts presented a mean age of  $78.00\pm9.20$  years (p=0.7489) and were predominantly female, accounting for 69.21% of the sample. No significant differences were observed in sociodemographics or disease severity between the groups, as indicated by MMSE scores (20.55 $\pm$ 5.93, p=0.0603) and CDR (p=0.0917). About 9% (p=0.7306) of cases between the groups received Chinese medicine combined therapy. However, the case management group demonstrated a significantly higher rate of COC (p<.0001), cognitive medication usage (p<.0001), hypnotics (p=0.0089), and anti-depressant consumption (p=0.0489). Furthermore, the case management group showed an increased utilization rate of daycare services (p=0.0517), a notably higher use of transportation services (p=0.0493), and a decreased reliance on long-term care facilities (p=0.0143).

**Conclusion:** The integrated WTCM case management model enhances COC, cognitive medication, daycare, and transportation long-term care services use; also lowers long-term care facility usage.



## Reminiscence: when the magic happens!

#### **Mrs Muriel Rason-Andriamaro**

Madagascar Alzheimer Association, Antananarivo, Madagascar

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

Madagascar Alzheimer's day care center opens 5 days a week to give quality time to people with dementia. Being synced to their mood is the key for beautiful moments together. How to be in phase with people living with dementia? Activities reminding the positive side of their past lives is one of the best ways to get their attention and spread positive feelings during their stay.

As a demonstration, we'd like to share two main cases observed in our centre during 2023:

- Aunt C. who is a former neurologist and unfortunately developed dementia: when we gently ask her to give advices for basic pain (headache for example), we notice that she immediately begins to talk a lot, sharing her experiences as a doctor. Everything she says still appears accurate and relevant, even if we can't take her recommandations as professional ones anymore During groups activities, she also takes her friends bloodpressure, and does it with a very good will. Feeling that she can always help people like she always did during her career, really changes her behavior, according to her husband who is her main caregiver.
- « Kalon'ny fahiny » is to name the old songs that we still love to hear and sing, at any age. One of our favourite activity is the musical one when we play a full list of « Kalon'ny fahiny ». The magic happens when everyone just stands up with beautiful smiles on their faces, to sing and dance together, remembering the exact lyrics and tone as if they didn't have any memory issues. This quality time full of spontaneity and joy make them very quiet and cool at home, according to their families.

Madagascar Alzheimer aims to develop most of its future activities around positive feelings coming from the PWD's past.



## 'I have learned to cope': How different caring styles can benefit from different support and resources

**Dr Elaine Mateus**<sup>1</sup>, Dr Ana Carolina Franzon<sup>2</sup>, Dr Mara Dellaroza<sup>3</sup>, Dr Tina Cartwright<sup>4</sup>, Dr Fauzia Knight<sup>4</sup>, Prof Damien Ridge<sup>4</sup>, Prof Catherine Loveday<sup>4</sup>

<sup>1</sup>febraz, Londrina, Brazil. <sup>2</sup>paho, Sao Paulo, Brazil. <sup>3</sup>universidade Estadual De Londrina, Londrina, Brazil. <sup>4</sup>university Of Westminster, London, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

In dementia care, family caregivers are pivotal, offering crucial emotional and practical support to those living with the condition. Their approaches to care are shaped by beliefs, knowledge, and available resources. Building a more in-depth understanding of the caring styles has important implications for future research and services. Our multinational study across the USA, UK, South Africa, and Brazil, carried out by researchers at the University of Westminster, in partnership with Alzheimer's Disease International (ADI) and Roche, aimed to understand the multifaceted experience of caring for someone with Alzheimer's. Roche provided funding and, alongside ADI, took part in the development and design of the study. In Brazil, the study was supported by the Brazilian Federation of Alzheimer's Associations (Febraz). Here we focus on how we have developed and implemented the findings in Brazil. Initially, 109 caregivers participated in an online survey, guiding the selection of 10 diverse interviewees. Utilizing semi-structured, in-depth interviews with photo-elicitation, and an inductive, iterative, and thematic analytical approach, we identified three distinct caregiving approaches. "Empaths" predominantly utilized emotion-focused strategies, deriving their caregiving roles from emotional narratives and benefiting from peer and professional support. "Organizers" employed problem-focused methods, blending existing and newly acquired skills for efficient home care, seeking structured training and professional guidance. "Reluctants" grappled with caregiver identity, lacking expertise and support, and preferred external assistance for caregiving responsibilities. Our preliminary findings guided the co-production of a video tool involving stakeholders such as individuals with mild cognitive impairment, care partners, journalists, and researchers. These varied caregiving styles underline the necessity for tailored support. By recognizing and accommodating these differences, future caregiving interventions and services can be more effective, ultimately enhancing the quality of life for both caregivers and those they care for.



## Community Based Services in the Care of Dementias/Major Neurocognitive Disorders: Our Experience.

Dr Tolulola Olufunto Taiwo, Ms Violet Tomlinson

Red Deer Regional Hospital Centre, Red Deer, Canada

#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

Aim: To Improve Access to Care Services in a Health Region/Zone.

**Method:** Community Based Geriatric Consultative Service is provided to Dementia patients living in their own homes as well as in residential care facilities. This service was borne out of the goal of ensuring access to geriatric care in those who are unable to attend clinic appointments. It has afforded us the opportunity to see persons living with dementia in their own environment.

Our Care Model comprises visits conducted by a Physician and the Community Geriatric Outreach Nurse.

A typical assessment comprises a chart review followed by an in-person visit. The visits comprise an meeting with the care partners as well as an opportunity to conduct a comprehensive review in the person's own environment.

**Results:** 967 persons were seen from September 2021 - September 2023. The assessments were conducted in private residences/home as well as in residential care facilities (lodges, supportive/assistive living residences and long-term care facilities/Nursing Homes).

**Conclusion:** Persons living with dementia should have access to good quality care. Proving community based services ensures access to individuals who would otherwise not have received these services.



## Integrated care pathways on dementia in Italy

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Aims:** Literature suggests that the implementation of integrated care pathways (ICPs) can be a crucial element in achieving the optimal management of people with dementia. Our study aims to identify the ICPs for dementia available in Italy and assess their compliance with the national guidance on ICPs for dementia.

**Method:** The ICPs were identified with i) the Italian Centers for Cognitive Disorders and Dementia survey conducted by the National Institute of Health; ii) research on the institutional websites of the Regions and Local Health Authorities (LHA); iii) e-mail to the general directorates of the LHA; iv) communication with experts. Documents produced after the guidance were included. Based on the national guidance a checklist was developed with 3 domains (Reference Context, Pathway Elements and Integrated Management, Local Pathway Construction) and 43 items (score 0-1). Two researchers conducted the evaluation blind, and a third researcher resolved the conflicts.

**Results:** A total of 69 documents were collected (28 regional, 41 local): 29 were included in the analysis (11 regional, 18 local). The mean total score was  $23.4 \pm 7.8$  for the ICPs of the Regions and  $22.7 \pm 5.7$  for those of the LHA. For the Regions, a range was found from 10/43 (Umbria) to 33/43 (Lombardy), while for LHA from 11/43 (Marca Trevigiana) to 31/43 (Naples2). The concordance analysis showed an excellent total score correlation for regional ICPs and a good one for local ICPs. No significant differences were observed between the mean scores assigned to the ICPs, both overall and in the individual domains.

**Conclusion:** The present analysis showed a relevant heterogeneity in compliance with the national guidance and outlined criticalities in the monitoring of ICPs and the coverage of the population. The publication of the guidelines on the diagnosis and treatment of dementia will make it necessary to update all ICPs.



## Differences of clinical phenotypes and demographics of old age mental telehealth service users residing in different regions in Greece

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#### **Topic**

Dementia diagnosis, treatment, care and support: Models of care

#### **Abstract**

**Background:** Older adults living in remote and low-resource areas across the globe cannot easily access mental healthcare services which are mainly based on tertiary or secondary hospitals. In this abstract, there are presented some of the primary results of Intrinsic regarding the differences in clinical phenotypes and demographic characteristics of users in relation to the geospatial regions of the primary healthcare centers.

**Methods:** The INTegRated InterveNtion of pSychogerlatric Care (INTRINSIC) network embodies a model of digitally interconnected tertiary old age mental healthcare services and primary healthcare services for seniors in remote areas in Greece. It relies on a digital platform, bridging healthcare professionals, service users, a battery of diagnostic tools, pharmacological treatment, and psychosocial support. The services are offered since May 2022 by eight primary healthcare centers which were divided into insular, rural and urban regions according to Hellenic Statistical Authority.

**Results:** 483 seniors living in remote areas have been enrolled in INTRINSIC. They are on average 75.2 years old and 68.1% are females. In insular regions users were older, more frequently lived alone, whereas in rural areas people tended to be less educated. Of note, prior their enrollment, only in 14.5% of service users the diagnosis of dementia had been established in insular regions, 3.3% in rural and 3.3% in urban regions. Respectively positive screening for dementia was established in 38% and for depression 24.5% in insular regions, 9.3% and 35.7% in rural and 17.6% and 19.3% in urban regions while cognitive complaints were present in 59.6% in urban regions, 45.5% in rural and 68.6% in insular regions.

**Conclusions:** The INTRINSIC model offers a pragmatic opportunity to provide high quality old age healthcare services to seniors living in remote communities. The still ongoing collection and analyses of service users' data may provide a solid foundation for INTRINSIC feasibility and sustainability.



# "Put yourself in our shoes": Family care partner perspectives of programs and services for older adults living in and around four RaDAR rural primary care memory clinics

**Ms Valerie Elliot**, Dr Debra Morgan, Dr Julie Kosteniuk, Ms Chelsie Cameron, Dr Megan E O'Connell University of Saskatchewan, Saskatoon, Canada

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Background:** In collaboration with primary care teams in southeast Saskatchewan, rural memory clinics (RMCs) evolved in four geographical areas. This study is part of an environmental scan of programs and services available in and around those four areas, that RMC patients and families might use. Our goal was to gain a deeper understanding of service-user experiences with those services, from their perspective, in their own voice.

**Methods:** Five semi-structured phone interviews were conducted from March to July 2022 with family care partners of people living with dementia. Interviews varied in length, were audiotaped, and transcribed. Data were analyzed quantitatively (frequencies/proportions) and qualitatively with thematic analysis using Braun and Clarke's (2006) six-phase approach. Transcripts were initially coded manually and subsequently coded in NVivo into meaningful themes. Themes were iteratively refined with review and discussion among study authors.

**Results:** Key interview themes reflected the need for locally available, accessible services that offer i) individualized, needs-based approaches, and continuity of care, ii) flexible in-home care options, and iii) both formal and informal supports. Gaps in services and recommendations to address were identified. In general, care partners indicated that service providers were more often female, program participants were mixed, and program content was gender neutral.

**Conclusions:** Drawing on the voices of family care partners was a key step in highlighting the service experiences, needs, and concerns of this population. Findings may inform future service delivery and interventions to help ensure perceived needs are met.



# Implementing research outputs in dementia care pathways: introducing the Dementia Toolkit and Cognitive Rehabilitation in the post diagnostic programmes of memory clinics

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

The IDEAL study at Exeter University is the only longitudinal study of factors aiding or hindering quality of life of people with dementia over an eight year period, and found that the key factors for positive outcomes are psychological in nature. Research into the effectiveness of Cognitive Rehabilitation approaches has been led by the same department. Both programmes combined and co-produced online and printed materials with people with dementia and care partners to make these accessible and useful to a wide audience.

Memory assessment and treatment services in the UK are established in every area, providing nationwide coverage and focusing on meeting targets of diagnosing a minimum of 2/3 of the expected incidence of dementia in each area. Given the increasing numbers due to the ageing population, and stagnating funding for these services, ever more resources are directed at diagnosis, while post-diagnostic support programmes aimed at living well with dementia are moved from specialist services in healthcare to less expensive services in the voluntary sector. Consequently, many services providing specialist adjustment to the diagnosis, developing coping strategies and maintaining a good quality of life are being lost.

In this context these newly developed resources (Dementia Toolkit, and My Life My Goals self help manual for Cognitive Rehabilitation) provide a vast resource of structured materials for people to regain hope, focus on what is important in their lives, find encouragement from others living with dementia, develop coping and compensatory strategies and find support and positive information for carers.

Our presentation gives an overview of the background and looks at the challenges of making materials accessible to large numbers of people with dementia and their carers following diagnosis in a Memory Service, looking at in depth survey results form people with dementia, carers and staff involved in the programme evaluating their usefulness.



## Implementing 'One Stop Shop' dementia review clinics: general practice innovations in dementia care during the PriDem Study

**Dr Sarah Griffiths**<sup>1</sup>, Ms Emily Spencer<sup>1</sup>, Ms Katie Flanagan<sup>1</sup>, Ms Jane Wilcock<sup>1</sup>, Prof Kate Walters<sup>1</sup>, Prof Louise Robinson<sup>2</sup>, Prof Greta Rait<sup>1</sup>

<sup>1</sup>UCL, London, United Kingdom. <sup>2</sup>Newcastle university, Newcastle, United Kingdom

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Background:** The PriDem: Primary care led post-diagnostic dementia care (2019-2023), UK Alzheimer's Society funded research programme, developed a flexible, primary care-based, post-diagnostic dementia care intervention. This comprises a Clinical Dementia Lead (CDL) supporting general practices to improve care systems, upskill the workforce, and enhance tailored care. A key focus is improving dementia annual review systems, addressing NHS England's commitment to personalised care planning. Researchers developed evidence-based review templates supporting this work.

An implementation study in London and Newcastle included seven general practices. Two CDLs delivered the intervention over 12 months. One way in which practices innovated was through 'One Stop Shop' dementia review clinics. People with dementia and carers attended on the same day and met with a range of practitioners (e.g., GPs, practice nurses, dementia advisors and social prescribers) and third sector supporters (e.g., Age UK) to cocreate care plans.

**Aim:** To understand the experiences of practitioners, patients, and carers of the 'One Stop Shop' dementia review clinics.

**Methods:** Observations and semi-structured interviews with people with dementia, carers and professionals were analysed using codebook thematic analysis. We report on a subset of findings relating to the 'One Stop Shop' dementia review clinics.

**Findings:** Motivated staff champions were crucial to implementation. Practices successfully adapted PriDem templates to fit their local needs. Running a series of clinics led to identifying areas for improvement, adapting and streamlining the process. Patients and carers reported experiencing increased care personalisation. Staff reported increased confidence relating to dementia care, optimism about long-term benefits (avoiding crises through proactive care), improved team working and enhanced patient relationships. Negative experiences included missed opportunities, e.g., lack of follow up post-review.

**Conclusion:** 'One Stop Shop' clinics were sustained beyond the lifetime of the PriDem study, demonstrating their potential as one approach to improving primary care led post-diagnostic dementia support.



## Forward with Dementia: ongoing development and promotion of an online post-diagnostic dementia support guide in the UK

**Dr Marie Poole**<sup>1</sup>, Dr Claudio Di Lorito<sup>2</sup>, Dr Monica Leverton<sup>3</sup>, Dr Kritika Samsi<sup>3</sup>, Ms Maud Hevink<sup>4</sup>, Prof Greta Rait<sup>2</sup>, Prof Louise Robinson<sup>1</sup>, Ms Jane Wilcock<sup>2</sup>

<sup>1</sup>Newcastle University, Newcastle, United Kingdom. <sup>2</sup>University College London, London, United Kingdom. <sup>3</sup>Kings College London, London, United Kingdom. <sup>4</sup>Maastricht University, Maastricht, Netherlands

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Aims** To help meet support needs after diagnosis, Forward with Dementia https://www. forwardwithdementia.org/en/ is a practical guide to help people living with dementia, families and health and social care professionals. The evidence-based guide was developed through international co-design with people living with dementia, family carers, a broad range of health and social care professionals, research teams and a brand consultant for social change (The COGNISANCE programme).

**Methods** In the UK, we have further developed the guide through additional interviews, iterative codesign workshops and user-testing. We have created new content to extend our reach and promote inclusivity, represent diversity in experiences of dementia; and have relevance for a broader range of health and social care professionals. We worked with people with lived experience of dementia and dementia support from diverse background and underserved communities including LGBTQIA+, people living with sensory impairment, ethnic communities, people with rare dementia diagnoses, people with young onset dementia, and regional diversity. We sought to explore how we could support homecare workers and social prescribers with crucial community support roles.

**Results** Findings supported the development of the guide to better meets the needs of a more inclusive audience. We have made change based on this evidence:

- Ongoing work to ensure content is updated and relevant
- Improved accessibility functions and content
- Creation of new content to support inclusivity and diversity new personal stories reflecting inclusive lived experiences
- New social media content
- New content for community and social care focusing on how to access social support as well as specific information for professionals.

**Conclusions** We continue to work collaboratively to improve and promote the guide, and secure its sustainability to ensure it remains a practical resource to enable people living with dementia and those who support them to access timely and appropriate information at a time of need.



## To explore the experience of people with dementia participating Dementia support group- playing Chinese chess.

Miss Shao-Ping Lin, Dr Chien-liang Liu, Miss Echin Huang, Miss Yu-chen Hsieh

Taipei City Hospital, Taipei, Taiwan

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Background:** In Taiwan, the most of the activities for people with dementia are more likely to feminine activities such as singing, drawing, or handicrafts else. In contrary, these activities do not suitable for men with dementia, even impact their participation.

**Method:** Taipei City Hospital Dementia Center offers the Chinese chess activity for people with dementia, once a week since April of 2023. In addition, Volunteers have been accompanied by playing chess else to the people with dementia, increasing the willingness of men with dementia would like to out of their house and participate in activities.

**Results:** At the beginning, only one person with dementia participated in Chinese chess activity. During 3 months, more than 5 male people with dementia participated in Chinese chess activity. Moreover, the people with dementia played Chinese chess games, while the dementia caregivers (all Female spouses) had been chatting and communicating on the side, sharing their experiences of daily lives, supporting each other and enjoying their break.

A volunteer who accompanied the chess player shared: A male with dementia suffers from Parkinson's disease. He usually drools and his hands shake, but when he plays chess, he does not drool. Although his hands still shake, it does not affect his chess playing.

Dementia Support Group - Playing Chinese chess allows people with dementia to gain dignity and a sense of accomplishment from playing Chinese chess, and also provides caregivers with dementia with mutual support and communication.



## **High Technology Wellness Activity Centres**

Ms Janine Lane<sup>1</sup>, Ms Elaine Mary Taylor-Whilde<sup>2</sup>

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

Dementia is a huge problem affecting over 55 million people, with 10 million new cases diagnosed each year. In the U.K. 944,000 people have dementia (Alzheimer's Research UK, Dementia Statistics Hub, 2023). For England the rise of people with dementia will reach 1,046,140 by 2030 and for the UK it will exceed 1.6million by 2050 (London School of Economics and Political Science (CPEC), 2019). This will result in increases in health and social care costs of £50.5 billion for England and £59.2billion for the whole of the UK by 2030 and increases to £80.4billion for England and £94.1billion for the UK by 2040. 1 in 3 people born in the UK this year, 2023, will develop dementia in their lifetime (Alzheimer's Research UK, Dementia Statistics Hub, 2023). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission identifies 12 modifiable risks, education, traumatic brain injury, hearing loss, hypertension, alcohol consumption, obesity, smoking, depression, social isolation, physical activity, diabetes and air pollution.

Primarily affecting people over the age of 65 we know

- Mental guickness reduces from age 25yrs (Harvard Health Publishing, 2017)
- Cognitive decline begins from age 45yrs (BMJ, 2012)
- Cognitive decline speeds up at retirement (Celidoni, Dal Bianco and Weber, 2017)

We aim to create state of the art high technology diagnostic and wellness activity centres. The progression of dementia can be slowed, and risks decreased if therapeutic interventions are started early. The Office of Health Economics showed that delaying the onset of dementia by five years (UK) from 2020 could reduce the projected number of people with dementia in 2050 by one third (666,000); reducing the need for informal care by 566,000. The costs of care would be reduced from  $\mathfrak{L}59$  billion to  $\mathfrak{L}$  38 billion in 2050; a saving of  $\mathfrak{L}21$  billion (OHE, 2020).



## Adjustment processes in caregivers of people with Alzheimer's disease

Prof Isabel Pereira Leal<sup>1</sup>, Dr Ana Margarida Cavaleiro<sup>2</sup>

<sup>1</sup>ISPA, Lisbon, Portugal. <sup>2</sup>Alzheimer Portugal, Lisbon, Portugal

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Objective:** This study aims to understand the process of adjustment of caregivers of people with Alzheimer's disease (generally and in specifying types of caregivers and care), through the relationships established between coping strategies, psychosocial variables, including: Anxiety, Depression, Stress, Satisfaction with Perceived Social Support, Quality of Life, Self-efficacy and socio-demographic variables.

**Methods:** It is a comparative study and correlation between formal (technicians and no technicians) and informal caregivers (n = 450) who will fill the Brief COPE (Ribeiro & Rodrigues, 2004), the SF-36 (Ferreira, 2000), Anxiety and Depression Scale Stress (Ribeiro, Honored & Leal, 2004), the Scale of Satisfaction with Social Support (Ribeiro, 1999), Self-Efficacy Scale for Caregivers of People with Dementia (Fortinsky et al., 2002, adaptation and validation into the Portuguese population) and a Questionnaire Socio-Demographic purpose built.

**Results and Discussion:** The results obtained allow us to see the need to establish intervention strategies, among caregivers, that promote interpersonal relationships, social activities and increase self-perceived physical and mental health. On the other hand, interventions should focus on the use of positive coping strategies and coping strategies based on humor.

**Conclusion:** With this presentation, we intend to establish intervention strategies that can provide caregivers with skills for more appropriate adjustment processes in order to a greater adaptability to the Alzheimer's disease and to the role of caring.



## Childhood Dementia Insight: A mixed-methods study investigating the psychosocial, quality of life, and psychological impacts of childhood dementia on families

**Dr Suzanne Mary Nevin**<sup>1,2</sup>, Prof Claire E Wakefield<sup>2,1</sup>, Dr Brittany C McGill<sup>1,2</sup>, Dr Kristina L Elvidge<sup>3</sup>, Miss Gail Hilton<sup>3</sup>, Mrs Megan Maack<sup>3</sup>, Mr Jason V Djafar<sup>1</sup>, Prof Michelle Farrar<sup>1</sup>, Dr Lauren Kelada<sup>1,2</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Background/Aims:** Childhood dementia is a devastating group of life-threatening and life-limiting disorders, defined by progressive decline of neurocognitive function and enduring loss of previously acquired developmental skills. Over 400 causal genes have been identified. However, less than five percent of these conditions currently have disease modifying therapies. Children with dementia and their families experience substantial bio-psychosocial impacts associated with the complex and idiosyncratic nature of this child's individually rare condition. Taking a collective approach, this research adopts an indepth mixed-methods approach to investigate the collective psychosocial impacts of childhood dementia on Australian parents and bereaved parents.

**Methods:** Parents will complete an online questionnaire including validated measures to quantify the perceived psychosocial, psychological and economic impacts of childhood dementia. Following completion of the online questionnaire, parents will be invited to participate in a one-on-one in-depth, semi-structured interview to elucidate parents' unique perspectives, experiences and impacts of their child's dementia on their family and to identify parents' unmet needs. A convergent, mixed-methods approach, combining the results from the quantitative and qualitative measures will be adopted to enhance interpretation of parents' experiences and to identify priority unmet needs.

**Results:** This presentation will quantify and qualify emergent themes reflecting the collective psychosocial, psychological and economic impacts of childhood dementia on Australian parents and bereaved parents.

**Conclusion:** Co-designed and evidence-based resources are crucially needed to provide integrated, multidisciplinary support for parents and bereaved parents of children with dementia. Our findings will inform future best-practice healthcare services and psychosocial supports for children and affected families.



## The effectiveness of self-care focused psychological support groups for people supporting ones living with dementia: a preliminary investigation

**Miss Wan-Ling Lin**<sup>1</sup>, Miss Ting-Yun Chou<sup>2</sup>, Ms Ya-Ching Shu<sup>3</sup>, Ms Shu-Chen Wang<sup>3</sup>, Ms Hsin-Yi Chou<sup>3</sup>, Ms Rou-Yu Hou<sup>3</sup>, Ms Shih-Chuan Wang<sup>4</sup>, Ms Yi-Chia Chuang<sup>4</sup>, Ms Hsing-Yi Chen<sup>4</sup>, Prof Chi-Cheng Yang<sup>1,5</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Objectives:** It is not uncommon for family care partners to take the needs of people living with dementia as the priority. They tend to focus more on the symptoms of dementia, behavioral and psychological symptoms, diet, and nutrition. As a result, care partners might overlook self-care unconsciously. However, it is known that self-care is essential, and this study thus aims to explore the effectiveness of self-care focused psychological support groups among Taiwanese care partners'.

**Method:** A total of 18 family members joined the self-care focused psychological support group from May to September 2023. Participants joined the group about emotional awareness, stress management, and relaxation exercises led by clinical psychologists. Participants joined the two-hour group once every two months. They received a psychological assessment, including The Distress Thermometer (DT), the Chinese Caregiver Burden Inventory in Dementia (CCBID), The Beck Anxiety Inventory (BAI), and the Beck Depression Inventory-Second Edition (BDI-II), before the session. The participants also evaluated DT and shared qualitative feedback after the end of each session.

**Results:** Our results showed that the mean total score of CCBID is 56.72 (SD=9.69) represented the potential increased stress levels from families, among which the highest score of five factors in CCBID is "Time-Dependence Burden" (M=14.81, SD=2.56). Additionally, almost all families reported anxiety (93%) and depression (81%). DT scores after the group were significantly lower than before the group (t=4.45, p=.000).

**Conclusion:** The self-care focused psychological support group was helpful in reducing family care partners' emotional distress. It appears the essentiality and needs of that psychological intervention for family partners. The long-term effect of the psychological support program and the further analysis of family partners' care burden might be needed in future studies.



## Home-visit counselling for people with mild dementiaa: A method that combines sandplay therapy and reminiscence work

Dr Yuzu Shimura<sup>1</sup>, Prof Masafumi Nagasaka<sup>2</sup>

<sup>1</sup>Meijo University, Nagoya, Japan. <sup>2</sup>Mikawa Hakoniwa Research Institute, Nagoya, Japan

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

In this practical study, we conducted a trial therapy that combined mini-sized sandplay therapy and reminiscent work for older adults with mild dementia. The therapist's attitude was simultaneously adjusted through documented self-reflection. A box for sandplay was prepared that was one-half the size of the international standard. The inside of the box was painted light blue, and about one third of the box was filled with sand such as people, animals, trees, plants, buildings, vehicles, and flounders can be freely combined and created freely within the framework of a box. After they had completed their creations, the participants were asked about their creations and simultaneously a simple lottery style question card was prepared and they were asked to introduce themselves.

The information they shared was compiled into a booklet that was later used to interact with the family. In the interaction with the families. During the interaction ,we asked the families to tell us anything they knew about their past. Question cards related to the newly added personal information will be added to the lottery type cards. The decision was made to help restore a sense of identity within reasonable limits. We tried to accept the elderly as they really are. In each session the therapist engaged in self-reflection through mindful breathing, relaxation, and writing technique while carefully examining the nature of the emotions experienced during the interaction.



# A multi-domain hearing and vision intervention for residents with dementia living in long-term care facilities: Intervention development

Prof Iracema Leroi<sup>1</sup>, Ms Erin Boland<sup>2</sup>, Mrs Brenda Buckley<sup>3</sup>, **Mr JP Connelly**<sup>2</sup>, Mr Niall Curley<sup>4</sup>, Prof Amr El Refaie<sup>5</sup>, Mr Matthew Gibb<sup>6</sup>, Dr Liz Graham<sup>7</sup>, Mr Brendan Lennon<sup>8</sup>, Prof Nicole Muller<sup>5</sup>, Ms Janice Palmer-Nolan<sup>3</sup>, Ms Valeria Raaft-Rezk<sup>2</sup>, Mrs Helen Rochford-Brennan<sup>3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Aims:** There is a high rate of unrecognised hearing and vision loss in people with dementia, particularly in long term care facilities (LTCF). This can worsen cognitive and functional decline and increase the impact on health resource utilisation. This paper describes the steps in modelling and developing a multi-faceted sensory health support intervention for residents with dementia (RwD) in LTCFs.

**Methods:** By means of a multistage process, a draft sensory support intervention (SSI) for LTCFs was developed in an iterative manner through collaboration with interdisciplinary health experts, LTCF professionals, researchers and Patient and Public Involvement (PPI) representatives. In stage 1, we developed the outline of an intervention by (1) extending an already evaluated home-based SSI conducted with individuals with mild-moderate dementia and hearing and/or vision loss living at home, (2) using evidence from a recent systematic survey of hearing rehabilitation for interventions for RwD in LTCFs; and (3) adapting a theoretical framework, the Sensory-Cognitive Model of Place. In stage 2, qualitative feedback from professional and PPI stakeholders on the draft intervention and intelligence regarding existing care sensory health training approaches were combined to produce a multi-component SSI-LTC ready for field testing in a single LTCF in stage 3. Based on feedback from this phase, final design modifications were implemented, and the final SSI-LTC prepared for pilot-feasibility trialing.

**Results:** The SSI-LTC comprises four components: (1) Resident level - personalised sensory health status check and record development, sensory assessment, device fitting, and adherence support; (2) Staff level – awareness training of care staff and Sensory Champions; (3) Environmental level – auditing and addressing sensory environments within the LTCF; and (4) Organisational level – auditing and addressing referral pathways to support RwD sensory-cognitive health.

**Conclusions:** We have successfully developed, and field tested a multi-tiered SSI suitable for trialing in LTCFs in a cluster randomised pilot trial.



## Implementation and dissemination of the individualized Meeting Centres Support Programme

#### Miss Channah Jamilla Osinga

Amsterdam UMC, Amsterdam, Netherlands

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Aims:** The individualized Meeting Centers Support Programme (iMCSP), consisting of DemenTalent (people with dementia work as volunteers in society based on their talents), Dementelcoach (telephone coaching for carers) and STAR e-Learning for carers, was developed as alternative or additional support by regular Meeting Centers for people with dementia and carers in 2019. The present project aims to get insight in the further implementation and dissemination of iMCSP.

**Method:** Two surveys were conducted in 2021 and 2023 among participants of a two-day course into implementation of iMCSP and people who requested the iMCSP manual (2021; N=49). The first survey contained questions about the status of iMCSP implementation, factors contributing to lack of implementation, quality of the iMCSP-course, and utilization of knowledge gained during the course and the implementation materials. The follow-up survey elaborated on facilitators and barriers in the implementation of iMCSP, using a theoretical implementation model (Meiland et al., 2004).

**Results:** The first survey showed that 43% of the respondents have (partially) implemented iMCSP, particularly DemenTalent and STAR e-Learning. Reasons for lack of implementation were COVID-19, personnel shortage, financial constraints, competing projects, complexity of DemenTalent and lack of need. The course and implementation materials were considered a strong foundation for implementing iMCSP. Only 12% sought external guidance for implementation, but 59% showed interest in seeking guidance in the future. Seven respondents applied for funding to implement iMCSP (70% successful), and 49% of organizations plan to implement iMCSP, with eleven seeking grants in 2022-2024. Results of the second survey about facilitators and barriers for implementation will be available late 2023. Results of both surveys will be presented at the congress.

**Conclusion:** There were several factors influencing further implementation and dissemination of iMCSP, such as COVID-19 and resource constraints. Based on both surveys recommendations on further dissemination of iMCSP will be provided.



# Effectiveness of structured cognitive training among patients diagnosed with late onset of Alzheimer's disease. Reports form a pilot study.

Miss Natalia Maria Segiet<sup>1</sup>, Miss Gabriela Początek<sup>2</sup>, Prof Aleksandra Klimkowicz-Mrowiec<sup>3</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Aims:** The aim of this study was to test the procedure and asses the effectiveness of structured cognitive training in patients diagnosed with late onset of Alzheimer's disease.

**Method:** Three patients (two women, one man) over 65 years of age diagnosed with late onset of Alzheimer's disease were enrolled in a study. Cognitive assessment (ACE-III, HADS,CVLT,TUS, go-no go test) was performed before and after 12 weeks of cognitive function training. During the 12 weeks of training, patients completed 24, hour-long sessions based on paper-and-pencil tests targeting 5 cognitive functions (two sessions per week). The tasks assessing cognitive function were prepared by the researchers. They were characterized by increasing level of difficulty. If a patient was absent from a session, he or she was given a task to complete at home and his or her completion was checked at the next visit

**Results:** Test-retest analysis of cognitive tests indicates possible positive effects of training. ACE III scores have increased by 6,7 and 17 points between screenings, respectively.

**Conclusions:** Preliminary observations showing a positive effect of cognitive training on the cognitive performance of patients with Alzheimer's disease are encouraging, but require confirmation on a larger number of subjects.



## "Evidence-informed and strengths-based rehabilitation: The role of Allied Health Professionals in Wales supporting people living with dementia, their carers and supporters."

Mrs Laura Braithwaite Stuart<sup>1</sup>, Dr Natalie Elliott<sup>2</sup>

<sup>1</sup>Betsi Cadwaladr University Health Board, Wrexham, United Kingdom. <sup>2</sup>Cardiff and Vale University Health Board, Cardiff, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Background:** The World Health Organisation global action plan for dementia (2017) highlighted rehabilitation as a key recommendation in rights-based care. Allied Health Professionals (AHPs) are leaders in rehabilitation, using strengths-based principles to help people achieve what matters to them. The AHP Dementia Framework for Wales was developed using an evidence-informed approach to understand current AHP practice across Wales and how this aligns with the empirical evidence.

**Methods:** Mixed methods were used to understand the rehabilitation offered by AHPs at 'Universal', 'Targeted' and 'Specialist' levels of support as part of a whole system tiered approach to care. A systematic scoping review was undertaken, utilising JBI methodology (Peters et al. 2020), to understand the outcomes of interventions provided by each of the 13 AHPs recognised in Wales when working with people living with dementia. Case studies were collected capturing emerging and innovative practice-based evidence. A national workforce survey identified opportunities and barriers for AHP services working with people living with dementia.

**Results:** Alongside case studies, the scoping review identified promising indications of efficacious AHP interventions in dementia. To maximise access to rehabilitation the workforce survey revealed areas for transformation including: funding, education, leadership, research and innovation.

**Conclusion:** People living with dementia and their carers are entitled to access person-centred rehabilitation. There is growing evidence regarding the impact of AHP interventions, care and support in dementia care. Without a cure, access to high quality rehabilitation that enables people to preserve independence and maintain wellbeing is key to living a life of quality post-diagnosis.

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## **Enhancing Cognitive and Social Engagement in Elderly Groups through a Museum-Inspired Card Game**

#### **Ms Wanching Peng**

Taipei City Hospital, Taipei, Taiwan

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

Board games are frequently used in group activities for elderly individuals with dementia or mild cognitive impairment. Board games offer a means to train various cognitive, social, and fine motor skills while providing entertainment that is generally well-received by seniors. However, existing board game products often suffer from issues such as small components, low recognizability, and limited relevance to seniors' daily lives, potentially affecting their effectiveness.

Taiwan's National Palace Museum has introduced a card game designed specifically for seniors, featuring antique artifacts as its theme. Classic national treasures are transformed into oversized cards, making them easier to handle, and the images on the cards are closely related to daily life, encompassing aspects like food, clothing, housing, and leisure activities.

The authors utilized this card game to design memory-based group activities tailored for elderly individuals with cognitive impairments. During these activities, seniors found the card content familiar, willingly shared past experiences of appreciating antiquities, and extended the discussions to aspects of their daily lives. The enlarged card size facilitated better visibility and handling for seniors. Compared to other board games, this card game received higher acceptance among seniors, proving easy to use and identify. Furthermore, its ability to connect with their past life experiences resulted in increased overall participation and more active engagement in discussions.



## **Connecting People Connecting Support: Occupation Matters.**

Prof Elaine Hunter<sup>1</sup>, Prof Claire Craig<sup>2</sup>, Ms Helen Fisher<sup>2</sup>, Ms Alison McKean<sup>1</sup>

<sup>1</sup>Alzheimer Scotland, Edinburgh, United Kingdom. <sup>2</sup>Sheffield Hallam University, Sheffield, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

The World Health Organization (WHO) recognizes dementia as a public health priority (2017) and their recent publication supports the role of rehabilitation in dementia care (2023). However, in spite of a growing evidence base showing the value of multi-disciplinary rehabilitation programmes for people with dementia, individuals are not routinely offered these services. This poster describes the use of digital platforms to support the call for accessible rehabilitation for people living with dementia.

Occupational therapists came together with researchers, designers and people with lived experience to develop an interactive website designed to help people embed health promoting activities into their daily routine. The interactive website was designed for people who wanted to keep well by taking steps to maintain good brain health, for people with mild-cognitive impairment or if the person had a diagnosis of dementia.

We will share how we designed the website to provide information, activities, and support using film, illustration and photography, is simple to navigate and information is easy to digest. To enhance the reach of the website, we will share how we integrated other digital platforms such as social media to enable people to learn about the website and contribute to it with a continued emphasis of lifestyle matters and the health benefits of occupation.

We will describe some of the learning and the impact, both in the UK and internationally, that has emerged from this practice innovation, particularly in relation what can be achieved through inter-sectorial working and the value of interdisciplinarity. We will end by sharing reflections of learning about best practice in design to support engagement and how insights developed from the project could potentially shape how and where occupational therapy is delivered in the future, sharing the transferability for an international audience.



## Different exercise interventions on neurocognitive performance in patients with Alzheimer's disease

#### **Prof Chia Liang Tsai**

National Cheng Kung University, Tainan, Taiwan

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Background:** Reduced neurocognitive functions are strongly associated with Alzheimer's disease (AD). Exercise plays an important role in AD management. However, how to design an effective exercise prescription to retard or even improve the neurocognitive impairment of AD is worth studying deeply. Purpose: To investigate the effects of Tai Chi Chuan and aerobic exercise on the neurocognitive performance of working memory (WM) in patients with AD.

**Methods:** Forty-two patients with AD were recruited and divided into three groups: Tai Chi Chuan exercise (TE, n=14), aerobic exercise (AE, n=14), and control (CG, n=14). Before and after a 4-month intervention period, neuropsychological [e.g., accuracy rates (ARs) and reaction times (RTs)] and neurophysiological [e.g., event-related potential (ERP) P3 latencies and amplitudes) performance were assessed in the patients with AD when performing a delayed matching S1-S2 paradigm.

**Results:** Although neither the TE nor the AE group showed a significant ARs benefit after a chronic exercise intervention, the TE group exhibited an improvement in P3 amplitude and the AE group exhibited significantly shorter RTs and larger P3 amplitudes when performing the WM task after the intervention period.

**Conclusions:** The present study supported the distinct effectiveness of Tai Chi Chuan and aerobic exercise for improving WM neurocognitive performance in patients with AD. These results have important implications regarding the use of the two exercise interventions for managing AD.



# Impact of special care unit for people with dementia and BPSD (SCU-B) on the management of behavioral and psychological symptoms of dementia (BPSD): insight from two italian centres

Dr Andrea Fabbo<sup>1</sup>, Dr Sara Fascendini<sup>2</sup>, Dr Barbara Manni<sup>3</sup>, Dr Emanuele Rocco Villani<sup>1</sup>

<sup>1</sup>AUSL MODENA UOC Geriatria - Disturbi Cognitivi e Demenze, Modena, Italy. <sup>2</sup>Centro Eccellenza Alzheimer Istituto Gazzaniga, Gazzaniga, Italy. <sup>3</sup>AUSL MODENA UOC Geriatria - Disturbi Cognitivi e Demenze, modena, Italy

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Background:** The management of behavioral and psychological symptoms of dementia (BPSD) needs dedicated approaches such as the special care unit for people with dementia and BPSD (SCU-B). SCU-B are residential medical structures, where patients are temporarily admitted if BPSD are not treatable at home. Aim of the present study is to compare the efficacy of SCU-B hospitalization on the impact of BPSD in two italian centers.

**Methods:** secondary analysis of the RECage-Respectful Caring for Agitated Elderly(RECage), a multicenter study involving eleven clinical centers with memory clinics and SCU-B facilities in seven European countries from 2018 to 2021. For the purpose of this study, the two italian clinics(AUSL Modena, Gazzaniga) were included. Diagnosis of Dementia was diagnosed according to DSM-IV, BPSD were evaluated on admission and at discharge according to the Neuropsychiatric Inventory(NPI).

**Results:** Of 88 patients enrolled at AUSL Modena, 10(11.4%) were admitted to the SCU-B. Of 62 patients enrolled Gazzaniga, 25(40.3%) were admitted to the SCU-B. The two populations were different in terms of mean age, being the patients form AUSL Modena older than those from Gazzaniga(79.6, 7.8 vs. 74.1, 7.9; p=0.003). Females were more represented in the Modena cohort(6, 60% vs. 11, 44%; p=0.012). Although the mean NPI, both at admission and at discharge, was higher in the Gazzaniga cohort compared to that from AUSL Modena(p<.05 for all), the median difference between the NPI at admission and at discharge was similar in both cohorts(-36.5 vs. -37; p=0.873). A significant difference was found in the mean length of stay, which was longer for the Gazzaniga cohort compared to that of the AUSL Modena(44 days vs. 24 days; p<.001).

**Discussion:** SCU-B hospitalization significantly reduces the burden of BPSD. Younger patients could need more time for their BPSD to be treated.





## P26-007

# Rehabilitation is a right for people living with dementia - partnership working between people with lived experience and allied health professionals in Scotland to promote and enable access

Mrs Alison McKean, Prof Elaine Hunter, Prof Scottish Dementia Working Group, Prof National Dementia Carers Action Network

Alzheimer Scotland, Edinburgh, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

### **Abstract**

**Background:** The right to rehabilitation for people living with dementia has remained a key commitment in the delivery of Scotland's Allied Health Professional (AHP) Dementia Policy, Connecting People, Connecting Support (2017). The World Health Organisation has developed a package of interventions for rehabilitation (2023) with dementia included in the neurological conditions module. It is recognised that "all people living with dementia can benefit from rehabilitation". The AHP Community are working in partnership with Active Voices (Scottish Dementia Working Group and National Dementia Carers Action Network) to amplify this fact and ensure that this right is understood and met.

**Method:** Based on close partnership working, we know that powerful outcomes are achieved when the voice and expertise of lived experience is combined with the voice and expertise of AHPs. Numerous innovative pieces of work have been undertaken and are ongoing, examples include:

Animations to share rehabilitation strategies which have been successful in maintaining independence and skills for people living with dementia.

- Films sharing experiences of the value of rehabilitation.
- Empowering the AHP student workforce via joint projects, workshops and education sessions.
- Publications including Blogs and a book 'Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia'
- Supporting national improvement projects

**Impact:** We will share examples of the work and the outcomes which include increasing knowledge and understanding, changing attitudes and challenging stigma (a key priority area for Active Voices).

**Next Steps:** Within Scotland's new dementia strategy, Dementia in Scotland: Everyone's Story (2023), there is a clear recommendation for support options to include rehabilitation. We understand that there is still work to be done in ensuring that this is accessible for "all people living with dementia". We will continue to build on our partnership working to strive towards this.



## Bronte Heath and Tim Beanland: Alzheimer's Society coordinated response to the UK cost-of living (CoL) crisis

Miss Bronte Arabella Carr Heath<sup>1,2</sup>, Mr Tim Beanland<sup>3</sup>

<sup>1</sup>Alzheimer's Society, UK, London, United Kingdom. <sup>2</sup>University College London, London, United Kingdom. <sup>3</sup>Alzheimer's Society, London, United Kingdom

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Social isolation, loneliness, depression and the consequences for people with dementia and carers

#### **Abstract**

From July 2022, Alzheimer's Society began to see a rise in CoL concerns raised by people affected by dementia. With a lack of published evidence, the Society sought to investigate the impact of the crisis and shape a coordinated response to best meet their needs. An internal group was formed to address four key questions:

- How is the CoL crisis going to impact people affected by dementia?
- What new services or builds on our current offers should we make as a result?
- What new fundraising activities do we need to make?
- What new communications messages do we need to raise awareness in the media?

We conducted a survey of 1,166 people affected by dementia in November 2022. Key findings revealed that nearly one in seven is cutting down on vital social activities, one in ten is cutting down or stopping social care, and more than half of those surveyed who live in their own home said they either don't leave home at all or go out for less than an hour a day; 45% of people living with dementia who live alone said they never go out.

Findings informed implementation of short- and long-term changes, including an online hub with CoL advice, a 10-point checklist for staff and volunteers to use as a prompt when supporting people affected by dementia, fundraising appeals and targeted media that reached 18% of all UK adults.

We are now launching a new national benefits service in partnership with UK Citizens Advice.



## An Improving Intervention Program For The Symptoms Related To Mourn And Burnout In Caregivers Of Alzheimer's Patients

#### Dr Mina Ahmadzadeh Gaskarimahaleh

Iran Alzheimer Association, Tehran, Iran, Islamic Republic of

### **Topic**

**Dementia diagnosis, treatment, care and support:** Social isolation, loneliness, depression and the consequences for people with dementia and carers

### **Abstract**

This study seeks to adapt the mourn intervention program to family caregivers of dementia patients and to evaluate its effectiveness in improving bereavement symptoms and other health-related variables in the grieving process. A total of 52 caregivers from the families of people with dementia participated. They were evaluated by using a series of self-report measures. The results indicate that this program improves the mourn symptoms of the caregivers and reduces the grief of the family. The result was effective. Therefore, due to the lack of programs that provide effective solutions for the mental and physical health of caregivers, and due to the human, social and economic costs of ignoring this issue, creating and implementing interventions targeting vague feelings of sadness and grief and helping Improving grief tolerance in caregivers is clear and obligatory.



# The impact of biopsychosocial frailty on Mild Cognitive Impairment (MCI) and Alzheimer's Disease (AD) Patients: Insights from a naturalistic study

**Dr Marina Charalampopoulou**, Dr Eleni-Zacharoula Georgiou, Dr Felemegas Panagiotis, Mrs Maria Skondra, Prof Panagiotis Alexopoulos

University of Patras, Patras, Greece

### **Topic**

**Dementia diagnosis, treatment, care and support:** Social isolation, loneliness, depression and the consequences for people with dementia and carers

#### **Abstract**

- \*Background:\* Understanding the multifaceted aspects of frailty in the context of neurodegenerative diseases like Mild Cognitive Impairment (MCI) and Alzheimer's Disease (AD) is crucial for comprehensive patient care. This study investigates the role of biopsychosocial frailty in MCI and AD patients within a naturalistic setting, with a particular focus on the relationship between frailty, cognitive function, and depressive symptoms.
- \*Methods:\* We conducted an observational study involving 39 control participants, 23 individuals diagnosed with MCI, and 16 AD patients. Comprehensive assessments included the Mini-Mental State Examination (MMSE), Cognitive Telephone Screening Instrument (COGTEL), Tilburg Frailty Indicator (TFI), and Montgomery-Asberg Depression Rating Scale (MADRS). Statistical analyses were performed to explore differences in TFI scores, physical frailty, and MADRS scores among the three groups.
- \*Results:\* Our findings reveal significant differences in TFI scores, indicating varying levels of frailty across the control, MCI, and AD groups. Notably, frailty, as measured by the TFI, was significantly higher in MCI and AD patients compared to controls, underscoring the association between frailty and cognitive impairment. Additionally, MADRS scores were significantly elevated in MCI and AD patients, highlighting the prevalence of depressive symptoms in these populations.
- \*Conclusion:\* This study provides valuable insights into the role of biopsychosocial frailty in MCI and AD patients within a naturalistic setting. The observed statistical significance in TFI scores, physical frailty, and MADRS scores among the groups underscores the complex interplay between frailty, cognitive decline, and depressive symptoms. Recognizing and addressing frailty in the context of MCI and AD is crucial for enhancing the holistic care of affected individuals. Our presentation at the conference will further delve into the implications of these findings for clinical practice and potential interventions.





## Together Stronger: Evaluating the impact of a creative arts program for children of parents with Young Onset Dementia

Ms Janet Goodman<sup>1</sup>, Ms Darya Moiseyeva<sup>1</sup>, Ms Phillippa Heath<sup>2</sup>, Ms Lizzie Harrison<sup>3</sup>, Ms Charlie Draper<sup>4</sup>, **Prof Arlene Astell**<sup>1,5,6,7</sup>

<sup>1</sup>University of Reading, Reading, United Kingdom. <sup>2</sup>Museum of English Rural Life, Reading, United Kingdom. <sup>3</sup>Berkshire Healthcare Foundation Trust, Reading, United Kingdom. <sup>4</sup>Younger People with Dementia, Reading, United Kingdom. <sup>5</sup>Northumbria University, Newcastle-upon-Tyne, United Kingdom. <sup>6</sup>University of Toronto, Toronto, Canada. <sup>7</sup>University Health Network, Toronto, Canada

## **Topic**

**Dementia diagnosis, treatment, care and support:** Social isolation, loneliness, depression and the consequences for people with dementia and carers

#### **Abstract**

**Background:** Young onset dementia impacts the individual and their families, including their children. There is a lack of specific supports and services for children and young adults who have apparent with Young Onset Dementia. We developed Together Stronger, a community based creative arts program for children of a parent with young onset dementia to examine the impact on social engagement and well-being.

Aims: Evaluate the impact of Together Stronger on children of parents with Young Onset Dementia.

**Method:** Eight children aged between 8-19 took part in Together Stronger, a joint program developed by Young People with Dementia (YPWD) charity, an Admiral Nurse and the Museum of English Rural Life (MERL) in Reading, UK, where the group was held. The program ran in a hybrid format over eight biweekly sessions, where activities included willow weaving, storytelling with museum artefacts, and baking together. We adopted a Participatory Action Research (PAR) approach to explore the impact on the children's well-being and social engagement.

**Results:** Qualitative analysis suggested an overall improvement in the well-being and social connection of the children and young adults. The young people were overwhelmingly positive about the creative activities and wished the group would continue. They valued the opportunity to spend time with other people who were in the same situation. However, they particularly liked the that the group did not focus on their parent's dementia but instead was about creative activities.

**Conclusion:** Our evaluation showed the feasibility, acceptability, and impact of this community-based creative arts program for children of parents with Young Onset Dementia. Engaging in creative activities with their peers was particularly highlighted. PAR was helpful in uncovering what was important to the children and young adults who provided useful recommendations on the structure and contents of the sessions for future service provision.



## We share our care and keep my mum really alive for ten years

#### Mrs Sladana Pavkovic Pavkovic

Wicking Dementia Research and Education Centre, Hobart, Australia

## **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

Serbia is not a part of European Union. This is an Eastern European Country where the family is a main support for people diagnosed with dementia, usually very late. The unmet needs of these people are treated with antipsychotics, and after several months they do not have any (un)met needs. This is how the medical practitioners "help" families to care about loved ones!

My aunty was diagnosed with dementia in 55. She lived in East of Serbia. She ended up in the mental institution and died in 59. Eleven years late, my mum was diagnosed with dementia in her 71. In Serbia, the health system in the provinces has not been improved very much from the time when my aunt was diagnosed to the time of my mum's diagnosis, but I have improved my knowledge. Dementia knowledge I had, helped me to bring my mum to the doctors, and get a timely diagnosis. I live in another continent, but for ten years I have provided tele-education to my sister and daughter. We all have our roles, and my sister was a main care who wonderfully replaced an occupational therapist, exercise physiologist, and the art therapist. We keep my mum alive, living a quality life filled with love and care. She died peacefully one month ago.

I hope to share the way of our care and strategies. This may inspire and give a hope to all people who do not live close to their loved ones with dementia.



## Employment support for people with younger onset dementia. Policy, practice and research implications for workforce re-entry.

#### **Mr Shane Dinnison**

University of Tasmania, Hobart, Australia

## **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

Dementia diagnosed earlier in life, nominally aged under 65, challenges identity, roles, finances, relationships, and employment, and is different from dementia later in life. Significantly, younger people with dementia overwhelmingly leave the workforce prior to or upon diagnosis, leaving them vulnerable to financial hardship and social exclusion. Options for workforce re-entry are scant.

Work is good for health, and there are persuasive economic, social and moral arguments that employment is an effective way to improve health outcomes for people with younger onset dementia.

In 2022, approximately 28,000 people are living with younger onset dementia in Australia (Australian Institute of Health and Welfare [AlHW], 2023). As international policy emphasises earlier screening and diagnostic tools improve, the number of people of working age diagnosed with dementia is likely to increase to approximately 39,000 in 2050 (AlHW, 2021). This paper outlines challenges for workforce re-entry for people with younger onset dementia. It locates the topic as multi-faceted, underresearched underappreciated, with reablement and rehabilitation efforts tainted by therapeutic nihilism. It demands action by policymakers, researchers, consumers, employers and advocates to address this emerging issue.



## Dementia Safety Center: Customized Case Management Operating Model for Dementia Patients

Ms Migyeong Kang<sup>1</sup>, Ms Kyunghae Lee<sup>1</sup>, Prof Jeewon Suh<sup>1,2</sup>, Prof ImSeok Koh<sup>1,2</sup>

<sup>1</sup>National Institute of Dementia, National Medical Center, Seoul, Korea, Republic of. <sup>2</sup>Department of Neurology, National Medical Center, Seoul, Korea, Republic of

#### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

With the expected increase in social burden due to rapid aging and the growing population of dementia patients, the government enacted the Dementia Management Act in 2011 and has been establishing dementia management plans every five years. In addition, in 2017, dementia safety centers were established nationwide in cities and counties to build a comprehensive dementia management system.

Dementia safety centers perform tasks such as early dementia screening, counseling, and education. They aim to alleviate blind spots in dementia patient care and enhance their quality of life through interdisciplinary collaboration, providing customized case management based on the demographic and situational characteristics of dementia patients.

Customized case management involves intervening with individuals categorized as emergency, intensive, or general management based on the demographic and situational characteristics of dementia patients. It consists of a total of 7 procedural steps and has a basic structure for intensive management of early-stage dementia patients.

Through initial assessments, the centers identify the needs and problems of the individuals and carry out customized management for each individual by coordinating with various community resources such as hospital-linked services, long-term care insurance for the elderly, public guardianship systems, and residential environment improvements.

In the future, dementia safety centers aim to fulfill their role as hubs of community dementia management by providing and coordinating customized services for patients based on connected information. To achieve this, they intend to present their specialized customized case management operating model unique to dementia safety centers



## National initial-phase intensive support team for dementia (IPIST) in Japan - history, performance, and challenges.

**Dr Kentaro Horibe**, Ms Yumi Shindo, Dr Shinichiro Maeshima, Dr Akinori Takeda, Dr Yukihiko Washimi National Center for Geriatrics and Gerontology, Obu, Japan

## **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

Back in 2012, the Ministry of Health, Labour and Welfare announced the new national dementia strategy, "Five-Year Plan for Promotion of Dementia Measures (Orange Plan)".

Initial-Phase Intensive Support Team for dementia (IPIST) programme was one of the newly designed programme in the Strategy, to support the people with dementia and their care partners at the earliest stage of the condition. It was launched in every city, town, and village in the country by the year of 2018.

IPIST is a multidisciplinary team comprised of medical professionals, such as Nurses, Public Health Nurses, Occupational Therapists, Certified Social Workers, and Certified Care Workers. When someone is suspected of having dementia or having trouble with the condition in their community, it makes home visits. After a thorough team assessment, it provides comprehensive and intensive initial (approximately up to six months) support, including information provision and linkage to appropriate services.

We, the National Center for Geriatrics and Gerontology, have been responsible for IPIST, from its launch to the member education programme up until the present.

Although IPIST was originally conceived for post-diagnostic support, the community need for early diagnosis has turned its direction towards early detection.

We will overview its history, performance, challenges, and future.



## Enhancing independence for people living alone with dementia: Insights from home-visit nurses

Dr Shuji Tsuda<sup>1</sup>, Ms Mayuko Ono<sup>1</sup>, Ms Tomoko Nakajima<sup>2</sup>, Dr Kae Ito<sup>1</sup>

<sup>1</sup>Tokyo Metropolitan Institute for Geriatrics and Gerontology, Tokyo, Japan. <sup>2</sup>Higashikurume Hakujuji Home-visit Nursing Station, Tokyo, Japan

### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

**Aims:** Dementia poses distinctive challenges for individuals living alone, as they lack the support of cohabitants, creating unique needs that must be addressed by home-visit nurses. These healthcare professionals play a vital role in interdisciplinary care teams, responsible for delivering both medical and long-term care. This study seeks to illuminate crucial strategies employed by home-visit nurses to promote independence at home among those living alone with dementia.

**Method:** Utilizing a qualitative research approach, this study employed purposive sampling across three home-visit nursing offices. Individual in-depth interviews were conducted with home-visit nurses to explore their experiences of caring for individuals living alone with dementia. Thematic analysis was applied to analyze the collected data, enabling the identification of key themes.

**Results:** Four themes were generated: Theme 1. Participation and whole-person understanding; Theme 2. Building personal support networks in the community; Theme 3. Co-production of solitary living; and Theme 4. Responsibility for collaborative decision-making. Each theme consisted of two or three subthemes, some of which were particularly relevant to observed living situations and addressed the specific needs of those living alone.

**Conclusion:** While the findings align with broader homecare practices across diverse living situations, they underscore the necessity for nuanced adaptations tailored to the unique context of solitary living. These insights provide a pathway for home-visit nurses, equipping them with a refined strategy for delivering targeted and effective support to meet the needs of individuals living alone with dementia.



## As a Builder, what can I do to help?

#### **Mr Neil Brickles**

Manchester City Council, Manchester, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

## **Abstract**

Lots within the home to allow independence and maintain home living. I have created a level access wet room complete with Dementia and RNIB approved products, used light reflectance values to identify issues and create contrasting blocks of matt tiles around appliances to enhance and identify what they are, tactile borders, enhanced focus point lighting to reduce glare and shadows, contrasting wall mounted shower seat, WC seat, and grab handles. matched the landing contrast so as not to create a visual barrier at the threshold of the bathroom.



## Psychoacoustics Cognitive Boost patch for Alzheimer's disease

#### Mr Dan Anzyo

NeuroAudit, Tel aviv, Israel

## **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

#### Psychoacoustics Cognitive Boost patch for Alzheimer's disease

NeuroAudit was founded in 2019 and has developed an innovative neurotechnology called psychoacoustics neuro stimulus, which is used to treat brain disorders via blood conduction.

The main application of NeuroAudit technology is in treating Alzheimer's disease, a neurodegenerative condition that causes memory loss, cognitive impairment, and behavioral changes. Using a new blood conduction technique, this noninvasive cognitive boost patch delivers a pure signal through the skin to the brain. NeuroAudit aims to improve the lives of millions of people suffering from brain disorders.

NeuroAudit offers a novel and effective therapy that can slow down or even reverse the cognitive decline caused by Alzheimer's disease by modulating specific brain regions and networks.

NeuroAudit's technology is tailored to each individual's brain activity, making it a personalized treatment for brain disorders and cognitive enhancement. It has the potential to revolutionize healthcare for those with neurological conditions and those suffering from chronic pain or depression.

In 2019, NeuroAudit was recognized as one of the top 27 Israeli neuroscience companies, and in 2020, it was recognized as "The Most Innovative Neurotech Company in The Middle East."

#### Our vision

NeuroAudit continues to make strides in developing new applications for their groundbreaking technology that has the potential to revolutionize healthcare for current and future generations.

Sincerely, NeuroAudit Team

Visit In Our Website: www.NeuroAudit-tech.com

Watch our Movie: youtu.be/RVuLLhluPoE



## Targeting terminal pathway in brain reduces complement activation and synapse loss in a mouse model of dementia.

Dr Wioleta Milena Zelek, Dr Ryan Bevan, Prof B. Paul Morgan

Dementia Research Institute, Cardiff, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

**Background:** Neuroinflammation is a critical component of Alzheimer's Disease (AD). Dysregulation of complement leads to excessive inflammation, direct damage to self-cells and propagation of injury. Membrane attack complex (MAC) is a highly pro-inflammatory product of complement activation, killing cells by lysis and/or causing sublytic damage, and provoking other damaging responses leading to death of vulnerable brain cells.

**Methods:** Role of MAC in AD was investigated in MAC-deficient animals and by using novel anti-C7 monoclonal antibody (mAb) that efficiently inhibits formation of the MAC *in vitro* and *in vivo*. Impact of C7 deficiency on brain complement dysregulation, synapse loss, amyloid load and cognitive decline was examined by comparing APPNL-G-F mice back-crossed to C7 deficiency with unmodified APPNL-G-F mice. To assess the effect of therapeutic C7 blockade, unmodified APPNL-G-F mice were treated systemically (for four weeks) with anti-C7 mAb or irrelevant control mAb.

**Results:** C7 deficiency in AppNL-G-F mice reduced levels of complement activation markers, reduced amyloid load and increased synapse density with a commensurate improvement in cognitive test performance. Systemic treatment of AppNL-G-F mice with a blocking anti-C7 mAb caused reduced brain levels of complement activation markers, reduced amyloid load, increased synapse density and cognitive function when compared to controls.

**Conclusions:** Complement dysregulation occurs in brain in the AppNL–G–F mouse model of AD. C7 deficiency and systemic C7-blockage reduced brain complement dysregulation, protected synapse loss and improved pathological parameters and cognitive function in the model.



## **Estimating demand for potential disease modifying therapies for Alzheimer's disease in the United Kingdom**

**Dr Axel AS Laurell**<sup>1,2</sup>, Dr Ashwin V Venkataraman<sup>3,4</sup>, Ms Tatjana Schmidt<sup>1</sup>, Dr Marcella Montagnese<sup>1</sup>, Dr Christoph Mueller<sup>3,4</sup>, Prof Robert Stewart<sup>3,4</sup>, Mr Jonathan Lewis<sup>2</sup>, Ms Clare Mundell<sup>2</sup>, Dr Jeremy D Isaacs<sup>5,6</sup>, Dr Mani S Krishnan<sup>7</sup>, Dr Robert Barber<sup>8</sup>, Dr Timothy Rittman<sup>1</sup>, Dr Benjamin R Underwood<sup>1,2</sup>

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### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

### **Abstract**

**Background:** The monoclonal antibodies aducanumab and lecanemab, which target brain amyloid, have received accelerated and full approval from the United States Food and Drug Administration for the treatment of Alzheimer's disease (AD) and a third drug, donanemab, is under consideration. However, concerns have been raised of the ability of healthcare systems to deliver these treatments considering the resources required for their administration and monitoring.

Aim: To estimate the scale of real-world demand of monoclonal antibodies for AD in the United Kingdom.

**Method:** We used anonymised patient record databases from two National Health Service trusts for the year 2019 to collect clinical, demographic, cognitive and neuroimaging data for these cohorts. Eligibility for treatment was assessed using the inclusion criteria from the clinical trials of donanemab and lecanemab (TRAILBLAZER-ALZ and CLARITY-AD) with consideration given to diagnosis, cognitive performance, cerebrovascular disease, and willingness to receive treatment.

**Results:** We examined the records of 82,386 people referred to services covering a population of around 2.2 million. After applying the trial criteria, we estimate that a maximum of 695 people per year would start treatment with monoclonal antibodies in the two services.

**Conclusions:** Monoclonal antibody treatment for AD is likely to present a significant challenge for healthcare services to deliver in terms of the neuroimaging required and the intensive nature of treatment delivery. However, this challenge would be comparable with the delivery of similar treatments for other conditions. The data provided here allows health services to understand the potential demand and plan accordingly.





## Ethical issues associated with early diagnosis of Alzheimer's disease and access to new anti-amyloid treatments

**Dr Serge Gauthier**, Dr Pedro Rosa-Neto, Mrs Claire Webster, Dr Jose A Morais McGill University, Montreal, Canada

### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

**Aims:** Identify the ethical issues associated with the diagnosis of MCI and mild dementia due to AD as well as access to anti-amyloid drugs to initiate a dialogue with stakeholders.

**Methods:** Search Google and PubMed using ethics, anti-amyloid drugs, and Alzheimer's disease as keywords.

**Results:** There are many publications since the overview by Leuzy & Gauthier (Expert Rev Neurother 2012;12(5),557-567) about ethical issues associated with the early diagnosis of AD. The emerging controversy is the label 'Alzheimer's disease' for asymptomatic people who are amyloid positive (alz. org/nia-aa). There have been editorials about the limited proof of clinical efficacy and the high costs of aducanumab, and more recent editorials since FDA approval of lecanemab and donanemab are addressing reimbursement issues (Carillo & Moreno JPAD 2023;3(10),346-348). An initial listing of resources required for the best use of these drugs can be found in the ADI World Alzheimer Report 2022 (Scheltens,302-303) and expanded in the latest Appropriate Use Recommendations for lecanemab (Cummings et al JPAD 2023;3(10),362-377).

**Conclusions:** There is a pressing need for people with MCI or mild dementia due to AD and clinicians involved in their care to hold discussions with decision-makers regarding access to new therapies that require screening in primary care, biological diagnosis in specialized centers, expensive treatments with close monitoring for complications, using finite human, technical and financial resources. Dissemination of results of such discussions will be through peer-reviewed publications, possibly a special ADI Report, and public education using virtual documents akin to Dementia, Your Companion Guide.



## Capacity of the health facilities manage Alzheimer's and related dementia diseases in Uganda: Challenges and recommendations

Mr Haruna Batange<sup>1,2</sup>, Dr Isaac Ddumba<sup>1,3</sup>

<sup>1</sup>African Research Center 4 Ageing & Dementia, Mukono, Uganda. <sup>2</sup>Mukono Municipal Council, Mukono, Uganda. <sup>3</sup>Victoria University, Kampala, Uganda

### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

### **Abstract**

**Background:** With the projected increase in number of older persons in both low and middle income countries, the burden of Alzheimer's and related dementia diseases (AD/ARDs) is projected to increase as well. However, the health systems inadequately prepared to offer optimal care for patients with AD/ARDs, despite the growing disease burden. Hence, the aim of this study was to assess the capacity of the health facilities to optimally manage Alzheimer's and related dementia diseases in Mukono district.

**Methods:** We conducted a cross-sectional between August and December 2018. A survey of 32 facilities (3 hospitals, 2 health center IV (HCIV), 15 health center III (HCIII) and 6 health center II (HCIII) and 6 Private health facilities) in Mukono district. We conducted a thorough assessment of medical records, interviewed heads of the facilities and questionnaire was administered to 46 health workers. The study assessed the service provision for AD/ARDs, Knowledge of AD/ARDs management, challenges and opportunities.

**Results:** Out of 32 health facilities assessed, 4 in 10 (42%)facilities reported managing (diagnosing/ treating) clients with AD/ARDs, and majority (90.2%) were run by Non-Physician Health Workers (NPHW). Only 2 in 10 of had guidelines for managing AD/ARDs. About less than half (46.4%) had AD/ARDs medicines in stocks (mainly Haloperidol) and all of the private facilities lacked essential medicine to treat AD/ARDs. All health center IIs lacked drugs for AD/ARDs. A significant knowledge gap in assessing and diagnosing AD/ARDs was observed among all the health workers. All health workers highlighted the need for addition training in AD/ARDs. Multitude of client and health provider challenges were observed in this study.

**Conclusion:** Health facilities in Mukono district are inadequately prepared to offer optimal services for management of AD/ARDs.



## Tackling ageism in the Caribbean

#### **Ms Rianna Patterson**

University College London, London, United Kingdom. Dominica Dementia Foundation, Roseau, Dominica

## **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

#### Introduction:

- Highlighting aging and living well in a cultural context. Creating a realistic and positive approach to older people in the media.
- Exploring holistic treatments for dementia and engaging in traditional dances in a quest to understand the recipe for the meaning of quality of life.

**Methods:** A qualitative study which comprised 7 respondents who are adults. This study was conducted using questionnaires, data was collected through an interview/documentary approach.

**Results:** Main messages were (1) dementia is not a normal part of aging, as younger onset dementia is apparent in Caribbean communities and (2) there is more to the person than their dementia, this includes goals and aspirations.

**Conclusion:** We have shown that it is possible to disseminate information effectively about Dementia in the Caribbean.



## Online health forum users' experiences and information needs regarding medicines for dementia: mixed methods analysis

Mr Chun Kit Shek<sup>1</sup>, Mr Mike Atkinson<sup>2</sup>, **Dr Carole Parsons**<sup>1</sup>

<sup>1</sup>Queen's University Belfast, Belfast, United Kingdom. <sup>2</sup>HealthUnlocked, CorEvitas LLC, Oxford, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Treatment and dementia

#### **Abstract**

**Introduction:** People with dementia and their family members and care partners often turn to Internet websites and forums as a source of information.

**Aims:** To explore and understand online health forum users' experiences of and information needs regarding dementia medications through qualitative and quantitative analysis of threads and posts on a large online health forum.

**Methods:** Analysis of de-identified posts and comments within discussion threads on the HealthUnlocked forum (www.healthunlocked.com), a UK online health forum launched in 2011 with over 1.5 million members and 315 public communities, covering more than 250 conditions. HealthUnlocked was searched from date of inception to 31st December 2022 using keywords specific to anti-dementia medicines. Forum user demographic information was analysed for each de-identified post (age, gender, ethnicity, country of residence) and posts were analysed using thematic analysis. Ethical approval was obtained from the University Faculty Research Ethics Committee.

**Results:** The dataset of de-identified posts contained 721 posts eligible for analysis. Of the posts where forum users specified their gender, over two-thirds (351; 68%) were female. Where age category was disclosed, over three-fifths of forum users were 65 years and over (254; 63%). The majority of forum users who disclosed country of residence were residents of the UK (199; 32%) or the USA (346; 56%). Data on ethnicity were available for 294 users, 258 of whom identified as White. Posts spanned the full duration of forum activity (2011 to 2022). Thematic analysis generated five themes: side-effects caused by dementia medicines, variation in effectiveness, dementia misdiagnosis, mistrust of healthcare professionals and 'Big Pharma' and seeking encouragement and support.

**Conclusions:** Healthcare professionals must acknowledge online communities as an important source of peer support and information and should work to improve relationships with, support for and experiences of people with dementia and their care partners regarding dementia medications.





## **Empowering Foreign Caregivers: Enhancing Dementia Care Skills** with STE2P Communication Model

Dr Chien-Liang Liu1, Mr Kai-Hsiang Chen2, Miss Nai-Yu Lin1, Miss Suh-Chin Wang3, Miss Liu-Yin Lin4, Prof Hung-Meng Huang5

1Dementia Center, Taipei City Hospital, Taipei, Taiwan. 2One-Forty, Taipei, Taiwan. 3Department of Health, Taipei City Government, Taipei, Taiwan. 4Long-Term Care Division, Department of Health, Taipei City Government, Taipei, Taiwan. 5Taipei City Hospital, Taipei, Taiwan

### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Aim:** Through interdisciplinary collaboration between healthcare and non-profit organizations, our goal is to enhance the dementia care skills of Indonesian domestic caregivers and their employers while reducing caregiving stress. This initiative aligns with UN Sustainable Development Goals (SDGs), particularly Goal 3 (Good Health and Well-being) and Goal 4 (Quality Education).

**Methods:** By the end of 2022, Taiwan had over 320,000 people living with dementia (PLWD), and the demand for caregivers was on the rise. Foreign caregivers played a pivotal role, assisting one in every five PLWD. In 2023, Taipei City Hospital's Dementia Center partnered with the non-profit organization, One-Forty to launch a complimentary "Foreign Caregiver's Dementia Care Training Program." This program commenced with online surveys of Indonesian domestic caregivers, covering caregiving challenges, communication skills (STE2P: Smile, Thanks, Eye contact, Embracing the moment, Patience), awareness, resources, and well-being. Focus group interviews addressed their difficulties in caregiving and communication.

**Results:** The analysis of 366 valid online surveys revealed three key issues: 60% of caregivers were uncertain about dementia symptoms, 76% encountered language barriers, and 27% experienced burnout, even among those with good relationships with PLWD. Ten Indonesian caregivers participated in two focus group interviews, discussing caregiving challenges and stress management. Data from surveys and interviews were used to create Indonesian and Chinese versions of the "Dementia Care Handbook." One workshop engaged 23 Indonesian caregivers, covering common symptoms, communication skills, stress management, and care resources. An Indonesian-language dementia care video was shared on social media, and an online support community for foreign caregivers was established.

**Conclusion:** Through interdisciplinary collaboration, we gained insights into the challenges faced by foreign caregivers. The handbooks, videos, workshops, and online support community aim to equip foreign caregivers with knowledge, improve caregiving skills, reduce stress, and enhance their confidence in dementia care, ultimately contributing to their well-being.



## **Hope vs. Despair: A New Paradigm in Memory Care**

Ms Sharon Johnson<sup>1</sup>, Ms Susannah Dwyer<sup>2</sup>

<sup>1</sup>Hearthstone Education Institute, Nashville, USA. <sup>2</sup>Abe's Garden Community, Nashville, USA

## **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

## **Abstract**

This inspirational presentation will provide insight into a major paradigm shift taking place in the field of dementia care: the realization that every care partner has the opportunity and the responsibility to make a positive difference in the lives of persons living with memory challenges. The presentation will discuss evidence-based strategies that enable people living with all stages of memory loss to continue to learn, achieve, and give back to their community.

For over two decades, the Hearthstone Institute has been a catalyst in shifting the prevailing "despair narrative" into one aimed at providing a life worth living for people who are experiencing the challenges associated with dementia. Citing examples from providers internationally, this presentation offers insight into what can be achieved when employing strategies that encourage people living with cognitive challenges to continue to be a part of their community, contributing to their living a meaningful, purposeful life regardless of the severity of their memory loss. Opportunities for continuous learning and connection will be explored as well as leading-edge programs including the Continuum of Cognitive Health™ and Learning for Life™. Research studies have demonstrated that the approaches used in these programs have a statistically significant positive effect on the following areas: Quality of Life (6% increase), Depression (41% decrease), engagement (28% increase), and anxiety (42% decrease).

The presentation will also discuss strategies that can help care partners provide authentic, engaging experiences to persons living with memory challenges throughout their lives, reducing the stigma associated with a dementia diagnosis.



## Effectiveness of Instrumental Activities of Daily Living program Based on the Familiarity for the People With Dementia in long-term care facilities: Focused Cooking Activities

**Mrs Yunhee Lee**<sup>1</sup>, **Mrs Eunsuk Choi**<sup>1</sup>, Miss Soyoung Oh<sup>1</sup>, Prof Jeonglan Kim<sup>1</sup>, Mr Joahyoung Cho<sup>2</sup>, Mr Byungyoon Yoo<sup>3</sup>

<sup>1</sup>sejong Dementia Center, Sejong, Korea, Republic Of. <sup>2</sup>village Of Love Group Home, Sejong, Korea, Republic Of. <sup>3</sup>sejong Woori Aged Care, Sejong, Korea, Republic Of

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Background:** and objectives of the study - The purpose of this study was to verify the effectiveness of instrumental activities of daily living programs based on familiarity for people with dementia at long-term care facilities and to provide basic data for the use and distribution of programs within the long-term care facilities.

**Methods:** The study was conducted in five long-term care facilities on 38 people with dementia from October to December 2021, per session in 60 min, 2 times a week for a total of 6 weeks. The main activities were six cooking activities familiar to the elderly with dementia, and the program room recreated the Korean kitchen space in the 1950s and 1970s using foam boards. Activities of daily living, instrumental activities of daily living, depression, agitation were measured before and after the intervention.

**Result:** Comparison before and after instrumental activities of daily living programs based on familiarity revealed that K-ADL (p<.373), K-IADL(p<.056), K-CSDD (p<.703) showed no significant difference, but the K-CMAI score significantly decreased(p<.005). As a result of the focus group interview, 4 topics and 8 subtopics were derived, The four topics were identified as experiences of familiarity remaining in the people with dementia, discovering the potential of the people with dementia, increasing positive emotional expression of the people with dementia, and opportunities for emotional communication with the people with dementia.

**Conclusion:** Instrumental activities familiar in everyday life can be effective in maintaining and strengthening emotional function in people with dementia. Long-term care facilities need to provide opportunities for instrumental daily activities familiar to the elderly with dementia. This helps identify remaining functions and unleash potential on people with dementia.



## Insights From Social Media Posts on The Lived Experience of Alzheimer's Disease

Dr Kristian Frederiksen<sup>1</sup>, Dr Rebecca Crawford<sup>2</sup>, Dr Julie Hahn-Pedersen<sup>3</sup>, Dr Ross Morrison<sup>2</sup>, Dr Rose Jeppesen<sup>3</sup>, Dr Lynda Doward<sup>2</sup>, Dr Wendy Weidner<sup>4</sup>, **Mr Niels Juul Brogaard**<sup>3</sup>

<sup>1</sup>Danish Dementia Research Centre, Department of Neurology, Rigshospitalet, University of Copenhagen, Copenhagen, Denmark. <sup>2</sup>RTI Health Solutions, Manchester, United Kingdom. <sup>3</sup>Novo Nordisk A/S, Søborg, Denmark. <sup>4</sup>Alzheimer's Disease International, London, United Kingdom

## **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Objectives:** To gain insights into the lived experience of Alzheimer's Disease (AD) for persons-living-with-AD (PwADs) from the perspective of PwADs and care partners using social media (SM) data.

**Methods:** Web-based searches of 4 sources: YouTube, Alzheimer's Association, Alzheimer Society of Canada, and Dementia UK. English-language SM posts between May 2011-May 2021 shared by PwADs/care partners/family members that discussed the lived experience of AD for PwADs were included. Data were analyzed thematically.

**Results:** 57 SM posts (24 blogs, 20 videos, 13 comments) shared by 74 contributors (18 PwADs; 56 PwAD care partners/family members) were included. 55 contributors (74.3%) discussed issues associated with AD diagnosis including observed subtle changes in the PwADs' wellbeing pre-diagnosis and challenges associated with attaining an AD diagnosis (e.g., delayed diagnosis). Notably, early AD signs/symptoms impeded PwADs' lives or were a cause of concern for care partners at least 12 months prior to a formal AD diagnosis. 43 contributors (58.1%) discussed AD-related symptoms: memory issues (n=26; 35.1%), confusion (n=12; 16.2%), and behavioural changes (n=9; 12.2%). Health-related-quality-of-life impacts included impaired well-being (n=24; 32.4%); notably, the stigma of AD being "an old person's disease" and impact of AD on PwADs activities/daily life (n=17;23.0%), work (n=12;16.2%), and social relationships (n=11;14.9%). 25 contributors (33.8%) commented on treatment experiences (e.g., decision-making).

**Conclusions:** This study provided valuable insights into the lived experience of people with AD. There is a detrimental impact on PwADs' health-related-quality-of-life often exacerbated by limited treatment options. Unsolicited SM posts may not be generalizable, but this unique data source offers access to important issues.



## "Don't you recognize me...?": Insights From Social Media Posts on The Impact of Alzheimer's Disease on Care Partners

Dr Kristian Frederiksen<sup>1</sup>, Dr Rebecca Crawford<sup>2</sup>, Dr Julie Hahn-Pederson<sup>3</sup>, Dr Ross Morrison<sup>2</sup>, Dr Rose Jeppesen<sup>3</sup>, Dr Lynda Doward<sup>2</sup>, Dr Wendy Weidner<sup>4</sup>, **Mr Niels Juul Brogaard**<sup>3</sup>

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## **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Background:** Alzheimer's disease (AD) impacts a care partners' daily life. We conducted a social media (SM) review to gain insights into impacts described by care partners.

**Methods:** SM data were identified from YouTube, Alzheimer's Association, Alzheimer Society of Canada, and Dementia UK. AD-related, English-language SM posts shared by persons-living-with-AD (PIADs)/care partners/family members (May 2011-May 2021) were reviewed and analyzed thematically.

**Results:** Of 279 posts identified, 65 met review criteria (26 blog posts, 22 videos, 17 comments). Of 89 contributors (17 PIADs; 71 care partners/family members; 1 PIAD and care partner), 78.7% (n=70) discussed impacts on care partners and family members. Areas affected included psychological and emotional well-being (n=53, 75.7%) and social life/relationships (n=37, 52.9%). Contributors reported impacts on overall quality of life (n=27, 38.6%), daily life (n=9, 12.9%), work and employment (n=8, 11.4%) and physical health (n=5, 7.1%). A profound theme was the emotional stress and sadness (n=24; 34.3%) of 'living bereavement'; i.e., the psychological receding of a loved one prior to their passing. Emotional stress was exacerbated by the PIAD's AD-related symptoms including altered behaviour and memory loss. Care prioritisation had long-term consequences for care partners including diminished wellbeing, personal sacrifices including loss of employment and financial impacts.

**Conclusions:** SM research explores experiences associated with caring for someone with AD. SM insights emphasized 'living bereavement' and the need for improved interventions to enable better management of this phenomenon. Care partners provided insights on psychological, social, and financial impairments associated with becoming a care partner, requiring further investigation.



## Dependency as a result of Alzheimer's disease across disease stages measured by activities of daily living

Dr Mercè Boada<sup>1</sup>, Dr Krista Lanctot<sup>2</sup>, Dr Pierre Tariot<sup>3</sup>, Dr Firas Dabbous<sup>4</sup>, Dr Julie Hviid Hahn-Pederson<sup>5</sup>, Dr Lars Lau Raket<sup>5</sup>, Dr Sariya Udayachalerm<sup>4</sup>, Dr Wojciech Michalak<sup>5</sup>, Dr Wendy Weidner<sup>6</sup>, Dr Luis Rafael Solís Tarazona<sup>5</sup>, Dr Jeffrey Cummings<sup>7</sup>, **Mr Niels Juul Brogaard**<sup>5</sup>

<sup>1</sup>Ace Alzheimer Centre, Barcelona, Spain. <sup>2</sup>Sunnybrook Research Institute, Toronto, Canada. <sup>3</sup>Banner Alzheimer's Institute, Phoenix, USA. <sup>4</sup>Evidera, Bethesda, USA. <sup>5</sup>Novo Nordisk A/S, Copenhagen, Denmark. <sup>6</sup>Alzheimer's Disease international, London, United Kingdom. <sup>7</sup>Chambers-Grundy Center for Transformative Neuroscience, UNLV, Las Vegas, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** To describe neuropsychiatric symptoms and ability to conduct activities of daily living (ADL) among participants with unimpaired cognition and Alzheimer's disease (AD).

**Methods:** Data from the National Alzheimer's Coordinating Center (NACC) Uniform Data Set were used for this study. The NACC collects annual follow-up data from participants seen at participating National Institute on Aging (NIA)-funded AD Research Centers. Participants with unimpaired cognition, clinically diagnosed mild cognitive impairment (MCI) or dementia due to AD were included. ADLs were assessed at each visit using the NACC-Functional Assessment Scale (FAS) and neuropsychiatric symptoms using the Neuropsychiatric Inventory Questionnaire (NPI-Q).

**Results:** The study included participants with unimpaired cognition (13,692 [48.5%]); MCI due to AD (7,075 [25.1%]); and dementia due to AD (7,453 [26.4%]). Participants' responses to individual NACC-FAS questions demonstrate that impact on ADLs may emerge as early as the MCI stage. For example, 0.4% of cognitively unimpaired participants were dependent on others when traveling out of the neighbourhood, driving, or arranging to take public transportation compared to 8.0%, 47.4%, 85.5% and 94.9% of participants with MCI due to AD, mild, moderate, and severe AD dementia, respectively. Similarly, 0.3% of cognitively unimpaired participants reported severe anxiety compared with 1.5%, 3.5%, 7.6% and 7.5% of participants with MCI due to AD, mild, moderate and severe AD dementia, respectively.

**Conclusion:** These data demonstrate that deterioration of ADLs and emergence of psychiatric symptoms are apparent as early as the MCI stage in the AD continuum and increase with disease progression.





## Subjective quality of life and service needs of rural primary health care memory clinic patients

**Dr Julie Kosteniuk**, Dr Debra Morgan, Dr Megan E. O'Connell, Ms Chelsie Cameron, Ms Valerie Elliot University of Saskatchewan, Saskatoon, Canada

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** Rural primary health care memory clinics provide interprofessional dementia diagnosis and post-diagnostic support in seven rural communities in southeast Saskatchewan, Canada (populations 332 to 11,019), reducing travel and wait time for specialist appointments. The aim of the current ongoing study is to explore self-reported quality of life and health/community service needs of patients at their initial appointment and 3 months later.

**Method:** Findings from the first semi-structured interview are presented with further results expected. The interview was conducted in-person/by telephone after the initial appointment. Questions explored subjective quality of life, related factors, and health/community service needs. Data were collected September 2021 to July 2023. Thematic analysis was undertaken with qualitative data and quantitative data were analyzed with descriptive statistics.

**Results:** To date, the first interview has been completed by 16 patients [75.4+12.1 (41-90 yrs); 14 female]. Most patients (62.5%) rated subjective quality of life as very good. Participants characterized good quality of life as happiness, being healthy, being comfortable/no problems, food/good home, family/ friends, time for oneself/keeping busy, being social, and enjoying nature. Themes identified in changes that could improve subjective quality of life included health/memory, living situation, finding something of interest, and 'nothing'. Most patients (87.5%) indicated they did not require further health/community services.

**Conclusion:** Preliminary findings revealed most rural memory clinic patients rated subjective quality of life positively and few reported needing further health/community services. Future analysis of 3-month follow-up data will provide further insight into quality of life of rural memory clinic patients and needs over time.



## Information Prescription-Building a Dementia-Friendly Community displayed on the Map – The Case of Taipei City

Miss Yi chieh Chu¹, Mr Chien -liang Liu¹, Miss Shao ping Lin¹, Prof Hung-meng Huang meng Huang²

<sup>1</sup>Dementia Center, Taipei City Hospital, Taipei, Taiwan. <sup>2</sup>Taipei City Hospital, Taipei, Taiwan

#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Background:** The study aims to view the effectiveness of implementing Information Prescription to create a specific map, which links appropriate referral services in Taipei City Hospital and provides easily readable information.

**Method:** Taipei City Hospital and the Department of Cultural Affairs, Taipei City Government collaborates in integrating different resources into an Information Prescription, presented on the map. Prior to designing the map, the Department of Cultural Affairs provided the information of local art and cultural institutions, which have easy-to-read pamphlets, to execute the plan. Finally, 38 venues were willing to become dementia-friendly spots and mapped out into the map.

The study findings are summarized as follows:

- 1. Information Prescription is feasible and applicable: To collaborate with local government's cultural agencies, it is easier to integrate numerous art-related and cultural places, including museums into the Information Prescription. Furthermore, it will be efficient through local government's cultural agencies to encourage cultural institutes and museums participating in Social Prescribing.
- 2. The benefits of Information Prescription: Through collaboration between the healthcare system and diverse venues, prescription can extend across various domains such as music, art, historical sites, and volunteering service. Social prescribing link workers in the healthcare system can provide prescriptions that are more suitable to the needs of individuals with dementia. Participants, by engaging in these activities, can promote mental health and quality of life, postpone disability, and alleviate caregiver stress.
- 3. The study suggests that Information Prescription is not only the non-pharmaceutical intervention, but also a provision of diverse referral resources in the healthcare system. In addition, it is more accessible for individuals to connect with public and private resources in local community through the link workers, enhancing social interactions and postponing disability. According to the study results and benefits, social prescription should be included in National Health Insurance as a long-term program.





## The experience of Shiatsu for care partners and persons living with dementia: A qualitative pilot study.

#### Ms Leisa Bellmore

University Health Network, Toronto, Canada

#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** The aim of this study was to explore shiatsu, a Japanese manual therapy, as a possible self-management strategy to relieve care partner stress and enhance engagement and connection for they and their partners living with dementia. Specifically, this study explored care partners' experience of using self-shiatsu and shiatsu with their partner living with dementia, and explored care partners' perceptions of the impact of shiatsu on the quality of their relationship.

**Methods:** This qualitative pilot study used an interpretive/descriptive approach. Participants were persons living with dementia and their care partners who attended programs at a facility associated with a large urban health sciences center. Care partners attended a workshop to learn self-shiatsu for stress management and a short, simplified shiatsu routine to use with their partner. Semi-structured interviews were conducted two and six weeks post-workshop to capture care partners' experiences and explore their ongoing use of shiatsu.

**Results:** Four care partners completed the study. They reported a broad range of experiences with shiatsu, representing four key themes: Enhanced Awareness, Integrating Shiatsu into the Relationship, Barriers and Facilitators and Potential and Possibility. Two care partners found self-shiatsu helpful. Two persons living with dementia were resistant to receiving shiatsu and two care partners felt shiatsu was an additional demand upon their time. Using shiatsu with their partners was a positive experience for only one, who felt it created closeness and connection. None of the participants felt using shiatsu with their partners affected their relationship quality.

**Conclusions:** The findings of this study are inconclusive. Self-shiatsu may be a beneficial self-management technique for some care partners, but not for others. Shiatsu for persons living with dementia may not fit some care partners' routines or lifestyles. For others, however, it may provide a meaningful way to engage and connect.



## **Exploring Sex-Based Differences in the Patient Journey of Alzheimer's Disease: A Survey Study**

Dr Alberto Ferrari<sup>1</sup>, Ms Ella Abken<sup>1,2</sup>, Ms Angela De Martini<sup>3</sup>, Ms Raphael Tiefenauer<sup>3</sup>, Ms Tunahan Kirabali<sup>3</sup>, Ms Julie Novakova Martinkova<sup>1,4</sup>, Dr Maria Carmela Tartaglia<sup>5,1</sup>, Ms Frances Catherine Quevenco<sup>1</sup>, Ms Maria Teresa Ferretti<sup>1</sup>, Prof Ann Marie Schumacher Dimech<sup>1</sup>, **Ms Laura Castro-Aldrete**<sup>1</sup>, **Ms Antonella Santuccione Chadha**<sup>1</sup>

<sup>1</sup>Women's Brain Project, Guntershausen, Switzerland. <sup>2</sup>London School of Hygiene and Tropical Medicine, London, United Kingdom. <sup>3</sup>Charles River Associates International, Zurich, Switzerland. <sup>4</sup>Cognitive Center, Department of Neurology, Charles University Second Faculty of Medicine and Motol University Hospital, Prague, Czech Republic. <sup>5</sup>Tanz Centre for Research in Neurodegenerative Diseases, Toronto, Canada

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** Understanding the unique experiences and challenges faced by individuals throughout the Alzheimer's patient journey. This study aims to investigate and emphasize sex- and gender-based differences in the responses of individuals at different stages of the Alzheimer's patient journey.

**Methods:** We conducted a comprehensive survey-based study targeting individuals who are experiencing the Alzheimer's patient journey, including those who suspected the disease, observed initial symptoms, sought medical advice, and those who have received a mild cognitive impairment (MCI) or a subjective cognitive decline (SCD) diagnosis. The survey included 79 structured questions related to various aspects of their journey. Sex and gender effect was tested with logistic regression (multinomial or ordered for multiple choice answers) and time to diagnosis was modeled using Cox regression.

**Results:** Our analysis included data from participants with MCI/prodromal AD (N=44), Mild AD (N=61) or Moderate AD (N=37) from USA and Germany, equally distributed between sexes. 38% of patients had confirmed Amyloid pathology. The results highlighted several significant sex differences in respondents' experiences and perspectives. Patient awareness: Men and women showed comparable awareness of risk factors for AD, but men showed increased awareness about sedentary lifestyle. Mode of Diagnosis: Diagnosis was most often performed by a specialist after referral from another doctor. Female patients, on average, were more likely to be diagnosed with MCI/AD after referral from another doctor and were more likely to do so prompted by forgetting recent conversations or events. Therapies and treatment: Female patients were more likely to be treated with reminiscence/life story work and to report benefits from it.

**Conclusion:** This survey-based study offers insights into sex and gender -based differences in the Alzheimer's patient journey. This survey is a proof-of-concept exercise that we aim to explore with a wider range of ethnic representation and a bigger sample size.



## **Promising Practices to Support those Living Alone with Dementia**

Ms Kate Gordon<sup>1</sup>, Mr Michael James Splaine<sup>2</sup>

<sup>1</sup>JHMI/Splaine Consulting, Columbia, USA. <sup>2</sup>Splaine Consulting, Columbia, USA

## **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

In Western Countries it is estimated that as many as 20% of those people living with dementia live solo. (PLAWD) Much of the work of Alzheimer organizations is rightly geared to supporting caregivers but what of this population?

PLAWD have higher unmet needs and are more susceptible to abuse and self-neglect than people with cognitive impairment who live with others (Lichtenberg et al., 2021; Portacolone, 2018). The most common unmet needs include assistance with basic activities of daily living, nutrition, medications, money management, and mobility (Edwards et al., 2020; Yang et al., 2022). Women report more difficulty getting their needs met than men, and Black and Latina women are more likely to report more difficulty getting their needs met than white women (Edwards et al., 2020).

This session will review promising practices including an online community and city level action summits to support PLAWD.



## Addressing mouth and teeth care for people living with dementia - the SORTED study

#### Dr Dia Soilemezi

University of Portsmouth, Portsmouth, United Kingdom

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Background:** Many people living with dementia are able to look after themselves but as dementia progresses, their family or home care workers are likely to help with personal care. If they cannot care for their teeth or mouth, they may be in pain, have problems eating, and need treatments. This is important to investigate as there is a strong link between dementia and poor oral health, and it is vital that dental needs are picked up as early as possible to prevent pain and unnecessary treatments for people living with dementia.

**Objectives:** The overall aim of the SORTED study was to explore ways of improving social care practice in integrating mouth and dental care into personal care for people living with dementia at home by examining how this is supported in individual assessments and care plans.

**Methods:** We carried out interviews with homecare staff, family carers and social care practitioners to explore their views on practices and challenges relating to assessing and delivering mouth and dental care. We also analysed care assessments to understand how oral and dental needs are discussed. Based on these findings and stakeholders engagement, we co-produced two checklists.

**Findings:** Participants acknowledged the importance of the oral and mouth care as a integral part of providing personal care to people living with dementia at home. They discussed challenges they face and several strategies they may use to engage people with dementia in looking after their teeth. Lack of guidelines, continuity of staff, time, knowledge were some of the barriers.

**Conclusions:** More information and training on oral care is required to raise awareness of the importance of preventative oral care in dementia. The study outputs could support these discussions between practitioners and people living with dementia and their families to ensure oral needs are addressed and supported adequately.



# At Home with Dementia - How increased understanding of dementia-friendly principles supports and improves the lives of people living with dementia and carers

Ms Renée de Wet<sup>1</sup>, **Dr Kaele Stokes**<sup>2</sup>, **Ms Barbra Williams**<sup>3</sup>

<sup>1</sup>Dementia Australia, Adelaide, Australia. <sup>2</sup>Dementia Australia, Melbourne, Australia. <sup>3</sup>Dementia Australia, Candelo, Australia

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

Dementia Australia's At Home with Dementia program, underpinned by the 10 principles of a Dementia Enabling Environment, assists people living with dementia or with mild cognitive impairment, their families, and carers to identify and implement strategies that result in environmental changes that support their independence, engagement, comfort, safety, wellbeing and participation in home life.

Specialist Dementia Occupational Therapists provide tailored education and advice.

This presentation will discuss 2023 program outcomes of support of 148 clients over 534 hours (target 500 hours) and includes impact of:

- increased understanding of positive and negative environmental impacts;
- increased knowledge of dementia-friendly environments;
- benefits of maximising independence, safety, and living well at home and,

case studies such as a couple wanting to keep the person living with dementia's desk tidy, reorganise some living spaces and plan a bathroom renovation using dementia-friendly design. They wanted to reconnect socially as they had lost friends and interests over the few years since diagnosis.

Through the program they decluttered and improved the desk organisation, decluttered living spaces and walkways to reduce risk of falls; arranged a separate OT assessment for bathroom renovation to include dementia-friendly design principles such as coloured toilet seats or raised toilet seats and modifications to reduce risks. They also followed up on attending Memory Lane Cafes, valued the socially stimulating activities and booked sessions with our Social Support Coordinator.

Feedback from another case study: "The night light has worked wonders. Jo sometimes wakes with a fright in the night and I say, 'look around you, there's a light on and you can see where you are' and in a couple of minutes she's back asleep. Thank you so much for that idea."



# Connecting people living with dementia to nature - supported holidays by Dementia Adventure to improve wellbeing and quality of life.

 $\hbox{Dr Manpreet K Gill, $M$s Fiona Petit}$ 

Dementia Adventure, Chelmsford, United Kingdom

## **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

Dementia Adventure is the only dementia support charity in the UK to focus solely on the importance of connection to nature and the outdoors. Our research shows there is a myriad of benefits to interacting with nature for people living with dementia (PLWD), which can include improvements in sleep, appetite and mood, and reductions in levels of stress and depression. In post-pandemic 2022 we delivered 31 supported dementia breaks in the UK, providing 179 holiday places. Taking place among natural surroundings, each of our holidays is purposely designed to maximise the wellbeing benefits of nature through contact with the natural environment and outdoor activities. Our evaluations found holidaymakers reported 78% had more exercise on holiday, 90% talked to more people than usual, and 94% enjoyed getting outdoors and connecting with nature. Additionally, our Carers Survey found that many carers and families simply cannot pay the price of a holiday, and since the pandemic and ongoing cost of living crisis there has been a drastic reduction in respite services. We found 82% of carers reported they felt they had a break from caring through our subsidised holidays that wouldn't have been possible otherwise. As a national charity we continue to think differently about dementia, aiming to support PLWD to foster enthusiasm for connecting with the natural world in their everyday life, as well as the security to do so on a regular basis. We challenge the stereotypes and perception of what it is to live with the condition, looking at what people can still do rather than what they can't.



## Developing an In-home Fitness Program for Persons with Dementia (PWD) within a Geriatric Care Management Model

Ms Laila Vehvilainen Malka, Young, USA

### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

### **Abstract**

There are approximately 6 million Americans age 65 and older with Alzheimer's disease or related dementia in the United States, of which 4.3 million live alone. Many have a limited social support network with adult children living in a different city or state, are widowed, divorced or never-married; reluctant to access and use health and social services. Using a geriatric care management model, the presenters' organization developed a customizable, in-home fitness program for persons with dementia (PWD).

There are a number of benefits for implementing this model based on organization's experiences: 1) PWD are more likely to engage and interact with a geriatric care manager who is also a fitness personal trainer. Exercise is an activity that is perceived with less stigma. 2) Physical activity or exercise is a non-pharmacological intervention for maintaining function, mobility and may reduce dementia related behavioral challenges such as disrupted sleep and/or agitation; 3) The personal trainer/geriatric care manager serves as a "first line worker" for identifying and addressing safety concerns, emergent issues and service needs. Research reveals that active management of Alzheimer's disease (AD) and other dementias improve the quality of life for PWD.

The presenters' will discuss the geriatric care management model and considerations for implementing an in-home fitness program for PWD; assessment of PWD using both geriatric care and validated fitness assessments; tools and templates for crafting a tailored resistance, aerobic, flexibility and balance exercises for mild and moderate dementia; and will review case studies of PWD using this model.



## Improving Research Concerning Long-Term Care Facility Residents with Dementia in Ireland

Mr JP Connelly<sup>1</sup>, Prof Iracema Leroi<sup>2</sup>, Prof Nicole Muller<sup>3</sup>, Prof Valerie Smith<sup>1</sup>

<sup>1</sup>Trinity College Dublin, Dublin, Ireland. <sup>2</sup>Global Brain Health Institute, Trinity College Dublin, Dublin, Ireland. <sup>3</sup>University College Cork, Cork, Ireland

#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** The number of long-term care facility (LTCF) residents with dementia (RwD) in Ireland is expected to rise significantly over the next two decades. Combined with an increasingly complex, higher dependency resident profile, LTCFs will face significant pressures to maintain care standards. Innovative, targeted solutions are urgently needed to meet these growing challenges but recruitment of LTCFs to research is very difficult. This research aims to improve research concerning RwD by (i) ascertaining barriers and facilitators to LTCF research participation, (ii) identifying research priorities concerning RwD.

**Method:** A pragmatic, mixed-method approach comprising a national survey (n=200) and one-to-one interviews (n=20) with LTCF manager/directors of nursing, care staff, RwD and family of RwD, proceeded by focus groups. Patient and Public Involvement (PPI) is embedded into the research process.

**Results:** Preliminary survey findings (n=67) suggest barriers to participation in research include concern about LTCF information falling into wrong hands and a belief that research will not benefit residents. Facilitators include trust in the person running the study, and study objectives and language that are easy to understand.

**Conclusions:** By articulating the research landscape in LTCFs in Ireland, this research will facilitate the design and delivery of more targeted interventions for RwD and help meet the specialised needs of the increasingly complex resident profile. It will also begin to lay the foundation for the creation of a research ready network of LTCFs based on the UK's Enabling Research in Care Homes (ENRICH) model.





## P31-001

## Preliminary Effects of Smart-Clothing Home Care on Older Persons Living with Dementia: A 3-Month Study

Prof Yea-Ing Lotus Shyu<sup>1</sup>, Ms Ya-Li Sung<sup>2</sup>, Dr Huei-Ling Huang<sup>2</sup>

<sup>1</sup>Chang Gung University, Taoyuan, Taiwan. <sup>2</sup>Chang Gung University of Science and Technology, Taoyuan, Taiwan

### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

### **Abstract**

**Background:** A novel smart-clothing home care model has been developed to support individuals living with dementia in a home setting. This study aims to investigate the initial impacts of this system on enhancing the overall functionality of older persons living with dementia.

**Methods:** The smart-clothing home care system was conceived to provide round-the-clock remote monitoring and transmit alert signals, such as nocturnal restlessness, irregular activity levels, wandering tendencies, and emergency calls. Personalized reminders and health education were delivered by home care nurses. The study encompassed a cohort of 17 participants who were exposed to the smart-clothing home care. Their cognitive function, activities of daily living (ADL) and instrumental ADL were assessed prior to the initiation of the smart-clothing intervention and at the 1st and 3rd months post-implementation.

**Results:** Following the adoption of the smart-clothing home care, participants demonstrated notable enhancements in MMSE scores (p=0.031) and IADL (p=0.034) within the first month. Intriguingly, these initial improvements did not remain prominent by the 3rd month after the implementation phase.

**Conclusion:** The utilization of smart-clothing home care presents promising benefits in terms of augmenting cognitive function and instrumental activities of daily living among individuals living with dementia, particularly within the first month of its implementation. To sustain and further enhance these improvements, it becomes imperative to devise and implement strategies tailored to the unique challenges and needs of this population. This study sets the stage for future research aimed at refining and extending the positive effects of the smart-clothing home care approach.



## P31-002

## Macroscale strctural covariance network reveals three distinct subetypes and abnormal patterns of neuropsychiatric symptoms in Alzheimer's disease continuum

Dr Jiwei Jiang<sup>1</sup>, Dr Kun Zhao<sup>2</sup>, Prof Jun Xu<sup>1</sup>

<sup>1</sup>Beijing Tiantan Hospital, Capital Medical University, Beijing, China. <sup>2</sup>Biomedical Engineering School of Biological Science and Medical Engineering Beihang University, Beijing, China

### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

### **Abstract**

**Objectives:** To identify the subtypes of neuropsychiatric symptoms (NPS) in Alzheimer's disease (AD) by using a regional radiomics similarity network (R2SN), and to characterize the abnormality patterns associated with the clinical and multimodal imaging features, and progression of each subtype.

**Methods:** An individual-level R2SN is constructed for N=550 {healthy controls (HCs)=63, patients without NPS (nNPS)=111, patients with NPS=376}. The R2SN profiles of patients with NPS were clustered using nonnegative matrix factorization. The patterns of brain alterations, clincial manifestations, multimodal neuroimaging, gene expression and clinical progression in each subtype were evaluated.

**Results:** Patients with NPS were clustered into three goups, severe NPS (sNPS, n=187), moderate NPS (moNPS, n=87), and mild NPS (miNPS, n=102). Significant differences were observed among three subtypes with respect to the following: 1) clinical measures (Patients with sNPS exhibited lower BMI and scores in the MMSE, MoCA and MNA, but higher scores in the NPI, ADL, and CBI than nNPS, but no significant difference in the MMSE and MoCA scores between miNPS and nNPS); 2) multimodal neuroimaging (Significant differences in the lateral occipital cortex, inferior temporal gyrus, medioventral occipital cortex, and fusiform gyrus of the altered morphological connectivity, brain volumes, cortical thickness, and cCBF); 3) the rate of clinical progression was faster in sNPS within 9.87± 3.28 months; 4) enriched genes for inorganic ion transmembrane transport and synaptic transmission.

**Conclusions:** Identification of NPS subtypes based on brain connectomes and a full understanding of heterogeneity could help clinical early diagnosis and intervention in AD continuum.



# Providemus alz: paving the way towards a ubiquitous and passive screening of Alzheimer's Disease

Mr Igor Matias, Prof Matthias Kliegel, Prof Katarzyna Wac

University of Geneva, Geneva, Switzerland

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

### **Abstract**

Alzheimer's disease (AD) is a pressing global health crisis with a soaring prevalence, imposing substantial societal and economic burdens. Early detection and intervention are pivotal in addressing this silent pandemic. The project Providemus Alz is motivated by the urgent need to combat AD. The core problem lies in the fact that AD initiates with subtle brain changes, such as the accumulation of amyloid beta, long before clinical symptoms manifest. Current diagnostic approaches are limited, leading to a substantial underdiagnosis rate. Providemus Alz proposes a pioneering approach to address this challenge.

Our research hinges on leveraging personal technology, including smartphones and wearables, to create digital biomarkers for early AD detection. We take a privacy-centric stance, passively collecting behavioral data from devices that individuals use daily. Our analysis delves into both interindividual and intraindividual variations in behavior to pinpoint the start of the preclinical phase of AD.

The project's first stage focuses on developing and validating machine learning techniques powered with composite outcomes that specifically target cognitive performance fluctuations in individuals with no cognitive impairment. Data collection will span up to two years to address feasibility and timeline constraints, initially centering on cognitive performance fluctuations. In essence, Providemus Alz strives to harness personal technology's potential, coupled with advanced machine learning, to pioneer the early detection of AD and thereby facilitate more effective prevention and intervention strategies.



The Welsh Ambulance Service provides unscheduled and planned services, including telephone and online advice. We support people affected by dementia as they access, use and move through our services. We have introduced a digital solution providing reminiscence therapy for dementia patients, who may become stressed and anxious in our environments.

#### **Miss Alison Johnstone**

Welsh Ambulance Services NHS Trust, Wales, United Kingdom

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

# **Abstract**

We receive safety reports, staff and patient feedback where our environments including vehicles, processes, and staff interactions have an impact on experiences and outcomes of people living with dementia when in our care. A lack of communication, reassurance and support, particularly in an emergency, can be distressing, confusing and cause anxiety.

"Develop a connection with me. Talk to me about what I like and don't like, the more you know about me the better".

"Listening to music and being distracted by different things will help".

Research tells us that people living with dementia benefit from distraction and occupation, which has led to the introduction of reminiscence therapy. Reminiscence Interactive Therapy Activities (RITA) is a digital solution using evidence-based therapies to develop more meaningful interactions with dementia patients. The resources in the software can provide distraction activities and different sensory experiences, including music, relaxation, games, films and more. We know that these opportunities support patients and carers on a long journey, on a long delay outside hospital or those who just require distraction due to boredom, distress, confusion or pain.

Case studies demonstrating the impact of RITA:

- On a 5 hour wait on the ambulance, the patient thoroughly enjoyed playing games and listening to the music which brought back good memories, and allowed them to sing along, remembering most of the words
- The patient loved listening to music and humming along. They were becoming restless whilst waiting but once we started using the tablet their mood settled.



# Classification of Brain bio-images for Alzheimer's disease using machine learning neural networks

Miss Poornima Dorairaj<sup>1,2</sup>, Mr Juhao Wu<sup>1</sup>

<sup>1</sup>SLAC National Accelerator Laboratory, Menlo Park, USA. <sup>2</sup>University of California Los Angeles, Los Angeles, USA

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

The rates of people being affected by Alzheimer's Disease (AD) have continued to steadily increase, with the disease currently accounting for roughly 60 to 80 percent of dementia cases and expected to affect more. Alzheimer's Disease can be broken down into three main stages: the cognitively normal (CN), mild cognitive impairment (MCI) with some loss of cognitive function, and the dementia stage. The focus of previous studies centered on avenues for early diagnosis which can delay the onset of the disease and reduce the cases of AD. However, these attempts have been thwarted by the difficulty of quantifying and identifying AD symptoms prior to the dementia stage, resulting in low discriminative accuracy in the CN and MCI stages. In contrast, current biological research emphasizes an observation of pathology, rather than symptoms, focusing on the accumulation of tau and amyloid beta plaques in the brain, culminating in a higher accuracy for early detection and diagnosis of the disease. The project aimed to incorporate this technique into brain bio-image classification methods for AD. We conducted neuroimaging analyses on MRI/PET bioimages from the Alzheimer's Disease Neuroimaging Initiative (ADNI) dataset using convolutional neural networks because of their sensitivity and reliability to deliver more precise classification compared to traditional cognitive assessments of the brain. Through optimizing different parameters in the script, we reached a test accuracy of 90.1 percent for classification, above the benchmark of current clinical accuracy for manual classification. To re-work the neural net's sensitivity, we conducted research into biomarkers like the APOE alleles, amyloid biomarkers, and tau-associated biomarkers that could improve the learning rate of our neural network. Besides further optimization, we are currently working on incorporating the identified biomarkers into our neural network to achieve higher thresholds of both sensitivity and efficiency.



# Preventive, screening system for early detection of dementia

Dr Mária Sátori<sup>1</sup>, Mr Zoltán Gelencsér<sup>2</sup>, Mrs Erika Simonová<sup>3</sup>, **Mr László Varga**<sup>4</sup>

<sup>1</sup>North Buda New Saint John's Hospital, SM Centrum, Budapest, Hungary. <sup>2</sup>Head Of Development, NETIS Ltd., Budapest, Hungary. <sup>3</sup>Quality and patient safety manager, health expert, ALSAD Medical, Budapest, Hungary. <sup>4</sup>Founder, innovation manager, NETIS Ltd., Budapest, Hungary

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Introduction:** The diagnosis of dementia is often delayed, which significantly worsens the prognosis. This poses several societal challenges, especially in terms of treatment and ensuring adequate quality of life. In Hungary, there is no available artificial intelligence algorithm that could help detect early signs of dementia based on the client's digital behavioral patterns.

**Method:** We used the PreDEM system for the early-stage assessment of dementia. In the two pilot periods, we gathered and analyzed over 8000 test data in 3 months in 2021 and over 9200 test data in 5 months in 2023. Participants completed the following tests: short international cognitive tests and games, Stroop tests, memory games, and other cognitive games. In addition, we compared various biomarker values. We created a standardized evaluation system for cognitive games to compare individual game results.

**Result:** Our results support the effectiveness of PreDEM. There was a significant difference between the results of individuals diagnosed with dementia and those from the healthy population. These differences will be well illustrated by the density functions of the results from various groups that we present. One of the highly significant observations during the study period is that cognitive game engagement notably improves individuals with memory issues. Many participants continued testing even after the study ended due to the pilot's success.

**Conclusion:** It can be stated that the PreDEM detected the first, otherwise imperceptible signs of dementia through artificial intelligence-based risk analysis. Early detection is vital as there's no cure; we must focus on improving conditions and monitoring through trend analysis. This allows for early intervention in case of a deteriorating trend. There is a need for preventive screening, as there is a clear correlation between preserved cognitive skills in later life stages and a reduced risk of Alzheimer's disease and dementia.



# Scoping Review of Serious Game-Based Interventions in Alzheimer's Disease and Mild Cognitive Impairment

Dr Mohamed Taiebine, Prof Abdelghafour Marfak, Prof Chakib Nejjari

The Euro-Mediterranean University In Fez (Uemf), Fez, Morocco

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

### **Abstract**

**Aims:** Due to the aging population and the lack of accessible pharmacological and non-pharmacological treatment, there is an increasing need to innovate in the field of neurodegenerative diseases. Beyond classical cognitive rehabilitation and training, the non-pharmacological interventions encompass serious game and virtual environments. The present scoping review aims to explore the gamification-based assessment and intervention in persons with Alzheimer's disease (AD) and Mild Cognitive Impairment (MCI).

**Methods:** A literature review was conducted in August 2023 following the framework of Arksey and O' Malley (2007) for scoping reviews. We searched articles published in English from 2000 to 2023 in PubMed, Web of Science and Scopus databases that addressed the gamification in AD and MCI. A total of 89 articles has been identified. Based on the inclusion criteria, 5 suitable studies were selected. Factors that contributed to the successful implementation of gamification, as per the literature, were described in terms of modality of intervention (assessment vs rehabilitation), type of devices, type of technology and outcome.

**Results:** Different studies used gamified assessment (n=1), gamified rehabilitation (n=2), cognitive one domain (n=1); cognitive multi-domain and non-cognitive (motor; psychomotor) (n=1). There are a number of intrinsic and extrinsic factors to take into account while using gamification for people with AD and MCI, including lack of self and hetero-motivation, poor engagement in long-term use of gamified applications in cognitive training; limited dexterity, digital literacy and numeracy and lack of trained healthcare for this population.

**Conclusions:** This scoping review showed the interest of developing innovative approaches in assessing and rehabilitation of cognitive and non-cognitive impairments in AD and MCI. There is a need to adapt the high and low-tech devices using a rationalized, evidence-based and gamified-based approaches for people from underserved and marginalized communities.



# **Brain Age Prediction Using Convolutional Neural Networks: Accurate and Efficient Model with Segment-Specific Images**

Miss Fatma Eltashani<sup>1</sup>, **Dr Fumie Costen**<sup>1</sup>, Dr Joao Papa<sup>2</sup>

<sup>1</sup>University of Manchester, Manchester, United Kingdom. <sup>2</sup>São Paulo State University, Brazil, Brazil

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Background:** Much interest has recently been drawn to brain age prediction due to the significant development in machine learning and image processing techniques. Studies based on brain magnetic resonance images (MRI) showed a strong relationship between the brain aging process and accelerated brain atrophy, suggesting using brain age prediction systems for early diagnosis of neurodegenerative disorders, such as Parkinson's, Schizophrenia, and Alzheimer's disease. Our work tackles two primary challenges that brain age estimation systems face: accuracy and computational speed.

**Method:** We develop a brain-age prediction system based on low-complexity 3D convolutional neural networks and magnetic resonance images with a dataset of healthy individuals covering the whole human lifespan (2,321 subjects, age range 5-89 years).

**Results:** We demonstrate accurate age prediction based on minimally preprocessed T-1 weighted grey matter brain scans with the smallest multi-site dataset including a wide age range for brain aging studies in the literature. We then show that using only specific segments of the brain scans can reduce the computational complexity and the excessive training time.

**Conclusions:** We argue that by using the bottom segment of the brain, the model can achieve comparable accuracy to the whole brain (MAE=5.378 and R2=0.909) while reducing the training time to one-third, i.e., from 19.678 hours to 7.066 hours.



# Technology Tours of the homes of people living with dementia: what devices they using and what are they using them for?

Ms Hira Awan<sup>1</sup>, Ms Danielle Pearson<sup>1</sup>, **Prof Arlene Astell**<sup>2,3,4,1</sup>

<sup>1</sup>University of Reading, Reading, United Kingdom. <sup>2</sup>Northumbria University, Newcastle-upon-Tyne, United Kingdom. <sup>3</sup>University of Toronto, Toronto, Canada. <sup>4</sup>University Health Network, Toronto, Canada

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Introduction:** Current technologies contain functions which can support cognition, such as storing telephone numbers and calendar reminders. These functions can benefit everyone, including people living with dementia. However, little is known about how people living with dementia use existing technologies and whether they are utilising these functions

**Objective:** To understand the technologies people living with dementia are using and how they use them in their daily lives.

**Method:** Technology Tours were completed in the homes of 9 individuals living with dementia, followed by semi-structured interviews. As they went around their homes the individuals were asked to describe what technologies they used in each room, what they used them for, and how they acquired them. The tours and interviews were transcribed and analysed using content analysis.

**Results:** Participants living with dementia described multiple technologies that they use in their everyday lives. These includes televisions, cookers and mobility aids, alongside tablets, smart phones, and voice assistants (e.g. Alexa). Their reasons were categorised into maintaining meaningful activities, staying connected, and independence, all of which influenced their well-being. Usability of devices and safety features were also highlighted.

**Conclusion:** The findings indicate that people living with dementia are using a wide range of technologies to support their everyday lives. They adopt different functions to support different aspects of their lives and would like to access more. However, the complexity of learning to use and incorporate some potentially helpful devices into their daily lives is a barrier. The findings can help to dispel myths about the interest and ability of people living with dementia to use digital supports, which can encourage wider use of readily available functions and devices.



# Needs Assessment for a Digital Medication Self-Management Tool for Persons with Mild Cognitive Impairment

**Ms Teresa S Warren**<sup>1</sup>, Dr Nila Silva de Albuquerque<sup>2</sup>, Ms Eliza Baby<sup>1</sup>, Dr Renato Ferreira Leitao Azevedo<sup>1</sup>, Mr Vincent Mathias<sup>1</sup>, Dr Timothy M Hale<sup>1</sup>, Dr Kathleen C Insel<sup>3</sup>, Dr Jeannie K Lee<sup>3</sup>, Dr Wendy A Rogers<sup>1</sup>, Dr Raksha A Mudar<sup>1</sup>

<sup>1</sup>University of Illinois Urbana-Champaign, Champaign, USA. <sup>2</sup>Federal University of Ceara, Fortaleza, Brazil. <sup>3</sup>University of Arizona, Tucson, USA

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

Persons with mild cognitive impairment (PwMCI) are at higher risk of medication nonadherence due to underlying deficits in prospective memory. Controlling co-morbid health conditions such as hypertension in PwMCI is critical to slow and possibly prevent progression to dementia. Leveraging the advances in mobile health (mHealth) technology to foster medication self-management is a viable strategy. However, little is known about the needs, preferences, and challenges for PwMCI to use mHealth technology to support medication self-management. Thus, we examined facilitators and barriers for using a mHealth app for the self-management of hypertension medications in eight older adults (M = 69.25, SD = 6.69) with subjective memory issues. Participants underwent a needs assessment, in which they saw a demonstration of the app then provided feedback about various features and rated different components of the app (i.e., medication home screen, medication tracking, education tabs). The facilitators identified by 87.5% of participants were the apps' ease of use and several engaging features on the app (e.g., medication reminders, records of medication adherence), and 50% of participants identified the welldesigned interface of the app. The barriers identified by 50% of participants were disengaging features (e.g., blood pressure functions and medication tracking) and 37.5% of participants were the lack of an option to personalize certain features (e.g., notification sound) and the effort involved in integrating the app into their daily medication-taking routine or when they are not comfortable using a smartphones. Participants also recognized that the app is currently limited to only hypertension medications, and they wished all their medications could be part of the app. Our preliminary findings support that PwMCl are open to using the mHealth app. However, the identified barriers also suggest that additional design components to enhance personalization and training to use the app might support better adoption.



# Supporting dementia caregivers in Peru through chatbots with Generative AI: mixed methods observational study

Dr Maria Sofia Cuba<sup>1</sup>, **Miss Fernanda Espinoza**<sup>2</sup>, Miss Miriam Lucar<sup>1</sup>, Dr Rafael A. Calvo<sup>2</sup>, Dr Jemma Hawkins<sup>3</sup>, Miss Maria Lazo<sup>1</sup>, Dr Antonio Bernabe<sup>1</sup>, Dr Chris R. Butler<sup>2</sup>, Dr Filipa Landeiro<sup>4</sup>, Miss Maria Kathia Cardenas<sup>1</sup>, Mr Carlos Vera<sup>5</sup>, Dr Graham Moore<sup>3</sup>

<sup>1</sup>Universidad Peruana Cayetano Heredia, Lima, Peru. <sup>2</sup>Imperial College London, London, United Kingdom. <sup>3</sup>Cardiff University, Cardiff, United Kingdom. <sup>4</sup>Oxford University, Oxford, United Kingdom. <sup>5</sup>-, Lima, Peru

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

Dementia caregivers face depression, stress, burnout and financial strain. Addressing their needs involves tackling the intricacies of caregiving and managing the emotional impact of supporting someone with dementia.

**Aim:** In preparation for the IMPACT project in Peru, we engaged with family members supporting someone with dementia in Peru, to understand their perceptions with chatbots offering care navigation and emotional support, with and without Generative AI (GAI).

**Method:** We divided the study into three phases: the initial stage encompassed engaging stakeholders to define design requirements for the chatbot; the second stage focused on the creation of 'Ana', a chatbot for dementia caregivers; and the final stage assessed the chatbot through interviews and a caregiver satisfaction survey. 'Ana' was tested in two configurations - one employed pre-defined conversation patterns, while the other harnessed GAI (e.g. chatGPT) for more dynamic responses.

**Results:** Caregivers sought immediate access to information on handling behavioural symptoms and a platform for emotional release. Moreover, they preferred the GAI alternative of Ana, as it was perceived to be more empathic and human-like. The GAI alternative scored above 4 for all metrics in the caregiver satisfaction survey (on a 1-5 scale), outperforming the version that did not employ GAI.

**Conclusion(s):** In conclusion, chatbots employing generative AI show promise in providing care navigation and emotional support to dementia caregivers in resource-restricted contexts at a satisfactory level.

Potential users valued the generative approach despite knowing the potential risk of receiving inaccurate information. This preference raises concerns regarding caregivers' preference towards potentially unsafe GAI chatbots, suggesting further investigation into the impact of GAI in dementia care.

This study is limited by the number of five participants and that they were all from Lima, so the results cannot be generalised, and they do not represent the perceptions of people from other regions.



# Development of a novel artificial intelligence intervention for augmented communications to sustain social interactions for persons living with cognitive impairment

**Dr Chitra Dorai**<sup>1</sup>, Ms Edith Stern<sup>1</sup>, Mr Sandeep Nagaraj<sup>2</sup>, Ms Vaishnavi Raveendranathan<sup>2</sup>, Ms Sreeranjini Seetharam<sup>2</sup>, Ms Sonam Pandey<sup>2</sup>, Ms Sharmilaa Balaganesh<sup>2</sup>

<sup>1</sup>Amicus Brain Innovations, Inc., Chappagua, New York, USA. <sup>2</sup>Amicalis Brain, Bengaluru, India

# **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Aim:** As dementia progresses, challenges in communicating effectively and the accompanying fear of loss of dignity in social interactions lead inevitably to social withdrawal and isolation of persons living with cognitive impairment (PLWCI). This further exacerbates the condition due to reduction in cognitive stimulation. Impoverished social connections with a shrinking set of trusted contacts, decreased interactions in quantity and quality, and loneliness are known to be modifiable risk factors for cognitive decline. However, little data exists to date regarding effective interventions to augment PLWCI communications in a personalized, assistive mode that can both maintain their agency and sustain effective interactions in social settings.

Therefore, we sought to develop and refine an artificial intelligence (AI) enabled adaptive, assistive intervention which compensates for declining capabilities by recommending contextually appropriate and personalized correct language forms and repairing what may be perceived as "broken" speech. Central to our approach is the continuous partnership with persons experiencing dementia in all phases of solution development.

**Methods:** In this paper, we present our approach for co-design with a purposefully sampled set of PLWCI and care partners from our local networks, which employs a mixed-methods, multi-phased strategy. In the first phase, we develop and iteratively revise a codebook and conduct recorded, semi-structured qualitative interviews using a standardized guide. In the second phase, we organize a design thinking workshop including representatives from stakeholder groups contributing to living well with dementia (clinical, social services, care partners and PLWCI). Integration of findings from the two phases guide the refinement and optimization of our Al intervention for eventual pilot testing.

**Conclusion:** We will summarize our findings from this multi-phased co-design approach where PLWCI and care partners are integrally engaged in the development of the intervention and user experience to deliver a transformational improvement in PLWCI lives.





# Wearable Neurovascular Monitoring in Alzheimer's Detection: The Al Revolution

### **Dr Arlene Fang**

MedTechX, Detroit, USA

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

### **Abstract**

Alzheimer's disease (AD), a primary cause of dementia in the elderly, has been continuously researched since its discovery by Dr. Alois Alzheimer in 1906. Early studies primarily focused on the role of neurotransmitters in cognitive decline. By the 1980s, attention shifted to proteins such as A-beta and Tau. Recent research emphasizes the importance of neurovascular coupling (NVC) in understanding AD, NVC plays a critical role in ensuring that brain regions receive the necessary nutrients and oxygen during neural activity.

Parallel to these insights, Artificial Intelligence (AI) has made significant strides since the mid-20th century. When combined with modern data science methods, AI offers innovative solutions, especially in healthcare. One such advancement is wearable technology, presenting new opportunities for health monitoring.

This paper explores the potential of Al-integrated wearables for early Alzheimer's detection, particularly the non-invasive monitoring of NVC and cerebral blood flow (CBF). While tools like fMRI and PET are precise, they face challenges related to cost and accessibility.

The integration of AI and wearable technology holds promise for advancing AD detection. However, it isn't without challenges, such as ensuring accuracy, managing large data volumes, and understanding user behavior and acceptance. Drawing from insights in neurology, technology, and data science, this paper remains optimistic. Given past successes in healthcare technology, the emergence of an AI-enhanced wearable designed for Alzheimer's detection is both achievable and imminent.



# **Enhancing Education and Training for professionals and formal carers: Implementing Microlearning**

Mr Darko Zrnic<sup>1</sup>, Ms Tracey Waldron<sup>2</sup>, Ms Kate Griffin<sup>3</sup>

<sup>1</sup>DSiDC, St. James Hospital, Dublin, Ireland. <sup>2</sup>Department of Clinical Nutrition and Dietetics, St James Hospital, Dublin, Ireland. <sup>3</sup>Speech and Language Therapy, St. James Hospital, Dublin, Ireland

# **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

"We are very busy here..."

"We don't have time..."

"We don't have enough staff..."

Staff shortages and heavier workloads has reduced the availability of health care staff to attend in-depth training courses. This, coupled with the recent moves away from traditional face-to-face learning to e-learning, we had to re-consider teaching theories and teaching methods.

In this presentation, we will demonstrate microlearning as an emerging pedagogy that enables learners and clinicians to engage in short, focused, asynchronous and just-in-time learning.

A 'mobile-first' platform delivers content to learners in bite-sized (5-10 minutes) bursts at the point of need, with a focused and specific learning outcome. The learner is in control of what and when they are learning, and can complete their training at a time and place that suits their busy schedule.

Additionally, the presentation will also emphasise how microlearning content can be shared through video, audio or short blocks of easily digested text, including the feature of AI videos. It is an efficient way of learning as it doesn't interrupt workflow. This allows for the maximum amount of learning and content retention in the shortest amount of time.

The presentation will explore the development and successful rollout of a microlearning module for hospital staff to improve the mealtime experience for people with dementia.

This novel microlearning platform is an effective and efficient way to upskill busy healthcare staff in issues affecting people with dementia and aims to encourage a culture of continuous learning and improvement among users.



### P32-001

Empowering Dementia Risk Reduction and Prevention: The topic aims to promote dementia risk reduction and prevention in Pakistan a densely populated country. It emphasizes clinical trials, innovation in low- and middle-income countries, community engagement, capacity building, transformative insights, and global impact in addressing challenges and opportunities in dementia care.

#### Ms Saima Jabbar

Islamabad, Islamabad, Pakistan

### **Topic**

Dementia research and innovation: Clinical trials in low- and middle-income countries

### **Abstract**

Dementia presents an escalating global challenge, with profound implications for individuals, families, and healthcare systems. This abstract directs attention to the critical realm of risk reduction and prevention, with a specific focus on Pakistan—a low- and middle-income country grappling with unique challenges in the face of this burgeoning crisis.

According to the United National Development Program Pakistan, the world's fifth most populous country in 2021, is a lower-middle-income country. Pakistan is a country where dementia awareness and its understanding are lacking and due to this, there are several cases of dementia going undiagnosed. Also, there is no specific national-level data registry and research available on dementia in Pakistan.

Pakistan's healthcare landscape is marked by resource limitations, but it is also characterized by resilience, adaptability, and untapped potential. This abstract examines the multifaceted approach taken to address dementia risk factors, clinical trials, and prevention strategies within Pakistan.

The following are key highlights of the abstract:

Risk Factor Identification: We look into the identification of dementia risk factors specific to the Pakistani population.

Clinical Trials in a Resource-Constrained Environment: We discuss the challenges and opportunities associated with conducting clinical trials in a low- and middle-income setting like Pakistan.

Community-Centric Interventions: Recognizing the role of community engagement in risk reduction, we showcase initiatives aimed at raising awareness, promoting healthy lifestyles, and providing support to individuals and families affected by dementia.

Capacity Enhancement: Capacity-building initiatives for healthcare professionals and researchers are examined.

International Collaborations: We highlight Pakistan's collaborations with global partners in dementia research.

In conclusion, this abstract underscores Pakistan's commitment to addressing dementia through a multifaceted approach that includes risk reduction and prevention strategies. Despite resource constraints, Pakistan's innovative clinical trials would inspire global collaborations and serve as an exemplar for low- and middle-income countries.



# Study on the Correlation between PM2.5 Exposure and Incidence of Alzheimer's Disease Among Seniors

### Dr Li Yang

Zhejiang Hospital, Hangzhou, China

# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

Studies have shown that PM2.5 may be associated with various neurogenic diseases represented by senile dementia. However, this topic has been little studied in Eastern China. We established a cohort of Alzheimer's Disease (AD) high-risk population. In 2018, the cohort of 1742 elderly aged 60 and above was established. In 2020, the cohort was followed up, a total of 1545 people participated the two surveys. Data collection included questionnaires and basic physical examinations. The PM2.5 exposure levels of the population in all the point locations were obtained by GIS software. We built 4 models including 1 unadjusted model and 3 adjusted models. This study showed that PM2.5 is an important factor that contributes to AD, and the average PM2.5 exposure levels among the study population were far above 10µg/m3 specified in the WHO air quality guidelines. There was a significant positive correlation between PM2.5 exposure and AD, and the correlations between PM2.5 and MMSE and MOCA scores were statistically significant and relevant. An increase in the PM2.5 level by 10µg/m3 could elevate the risk of AD among residents by 2%-5% (HR=1.02 to 1.05). The senior group and those who had low educational degrees, who used to work as farmers or blue-collar workers before retirement, and those who were overweight and obese were faced with a higher risk of AD incidence and reported lower MMSE and MOCA scores. The suggestion is to reduce PM2.5 exposure as a means to prevent dementia. This is likely to bring huge health benefits.



# Cohort Study of the Effects of Occupation and Environmental Tobacco Smoke on the Incidence of Alzheimer's Disease Among Seniors

Dr Li Yang

Zhejiang Hospital, Hangzhou, China

# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

Alzheimer's disease (AD) is a disease caused by manifold factors, among which occupational and environmental factors have a part to play. Environmental tobacco smoke (ETS) can affect cognitive function. We established a cohort of AD high-risk population. In 2018, the cohort of 1742 elderly aged 60 and above was established. In 2020, the cohort was followed up, a total of 1545 people participated the two surveys. Data collection included demographic economic information such as age, gender, occupation, education level, etc., and relative health behavior information, such as smoking, drinking and tea drinking, etc. Basic physical examination data included height, weight, Blood pressure (BP), etc. At the same time, related cognitive status was assessed. Cox proportional hazards regression model including unadjusted model and adjusted model were used to determine the relationship. The results showed that ETS exposure and occupational characteristics were associated with the increased risk of cognitive impairments in seniors, subgroups who used to work as blue-collar workers, who never worked, who kept standing for most of the time at work, and who were engaged in hard physical labor work prior to retirement had high incidence rates of AD. It revealed that ETS, standing for most of the time and hard physical labor work were associated risk factors of AD among seniors, compared with that of white-collar work. We recommend that the government establish a community supervisory mechanism to persuade smokers to quit or control smoking.



# Predicting patients with dementia most at risk of needing psychiatric inpatient or enhanced community care using routinely collected clinical data: a retrospective multi-site cohort study

**Ms Sabina R London**<sup>1,2</sup>, Dr Shanquan Chen<sup>1,3</sup>, Dr Emad Sidhom<sup>1,4</sup>, Mr Jonathan R Lewis<sup>4</sup>, Dr Emma Wolverson<sup>5</sup>, Dr Rudolf N Cardinal<sup>1,4</sup>, Dr David Roalf<sup>2</sup>, Dr Christoph Mueller<sup>6</sup>, Dr Benjamin R Underwood<sup>1,4</sup>

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# **Topic**

Dementia research and innovation: Epidemiology

### Abstract

**Background:** Dementia affects 55 million people around the globe and is devastating to patients and their families. In the UK, patients are diagnosed with dementia in memory assessment clinics and then discharged to primary care until a significant deterioration results in the need for more intensive support.

**Aims:** The aim of this study was to identify at diagnosis patients with dementia who are most at risk of deteriorating, which could allow the development of interventions with the goal of preventing psychiatric hospitalizations.

**Method:** We examined anonymized records of 27,313 patients from two United Kingdom NHS Trusts, using cognitive, clinical, and demographic variables from the time of diagnosis. This the largest data set to date examined to predict the need for enhanced community care for patients with dementia.

**Results:** Less than 15% of patients required intensive care. In both datasets, patients who were younger (p<0.01) and had lower HoNOS subscores for disability (p<0.05) were more likely to be hospitalized (a lower HoNOS score indicates a less serious problem). Differences observed in London included that patients from more disadvantaged areas were more likely to need enhanced care (p<0.05). Patients who were hospitalized could be predicted using logistic regression with an area under the ROC curve greater than 0.7.

**Conclusions:** Variables at time of diagnosis identified a group of patients who were high-risk, suggesting that identifying this small group is key to targeting interventions to allow patients to stay in their own homes.



# Progression from all-cause mild cognitive impairment to Alzheimer's disease in UK Biobank: epidemiology, healthcare resource utilisation and costs

Prof Craig Ritchie<sup>1,2</sup>, Dr Sophie Edwards<sup>3</sup>, Dr Dominic Trepel<sup>4</sup>, Dr Julie Hviid Hahn-Pedersen<sup>5</sup>, Dr Mei Sum Chan<sup>6</sup>, Dr Ben Bray<sup>6</sup>, Dr Alice Clark<sup>5</sup>, Mr Christian Ahmad Wichmann<sup>5</sup>, Dr Alex Mourer<sup>5</sup>, Dr Marc Evans<sup>7</sup>, **Mr Niels Juul Brogaard**<sup>5</sup>

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#### **Topic**

Dementia research and innovation: Epidemiology

### **Abstract**

**Aims:** To describe the natural history, healthcare resource utilisation and costs of progression from all-cause mild cognitive impairment (MCI) to Alzheimer's disease dementia (ADD).

**Method:** UK Biobank participants were followed until end of primary care or hospital record linkage or loss to follow-up. Cognitive tests at baseline were utilised to identify participants with cognition scores consistent with MCI, using principal component analysis. Participants with and without MCI were matched using propensity scores to compare healthcare utilisation and costs. Progression to ADD was defined using diagnostic codes in electronic health records.

**Results:** Of 164,508 participants with cognitive assessment data, 6,605 (4%) had evidence of all-cause MCI. Incident rates of ADD were 9.5 times higher (95% CI, 7.9-10.9) for participants with versus without MCI at 5 years. 5,419 participants with MCI were matched to 21,676 without MCI, 40% of which had linked primary care records. Hospital inpatient costs were £866 (Standard Deviation, SD £3,205) per person per year in the MCI population compared to £789 (SD £3,479) in matched participants without MCI, and £1,978 (SD £8,890) versus £1,669 (SD £9,096) 10 years after baseline, whilst primary care and prescription costs over 6 years were 9.6% higher in those with MCI. The difference in cumulative inpatient costs over 10 years between those with (n=75) and without (n=5344) eventual ADD diagnosis was £20,200 per participant with MCI.

**Conclusions:** Hospital and primary care costs in individuals with cognition scores consistent with MCI are modestly higher overall and much higher in individuals who subsequently develop ADD.



# Dementia, Functional impairment and Disability among the community residing elderly people(aged≥60) in Nepal.

**Ms Prekshya Thapa**<sup>1,2</sup>, Dr Stella Maria Paddick<sup>3</sup>, Dr Ammu Lukose<sup>4</sup>, Dr Nidesh Sapkota<sup>5</sup>, Dr Mathew Varghese<sup>6</sup>, Dr Richard Walker<sup>3</sup>

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# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Background:** The much-needed studies on local epidemiological and psychosocial burden of dementia and disability among elderly is lacking in Nepal which are needed for planning and policy making. Thus, this community-based study was conducted to screen Dementia, Functional impairment and Disability among community residing elderly people.

Methods: This was a one-stage house to house cross-sectional epidemiological survey of all individuals aged ≥60 years in two wards of Dharan Sub Metropolitan City, Nepal. Measures used were Informant Questionnaire on Cognitive Decline (IQCODE) and Brief Community Screening Instrument for dementia (CSI-D), Everyday Ability Scale (EASI) and Barthel Index. Data were collected by trained nurses from December 2021 to March 2022 using Kobo toolbox software and analyzed using SPSS-16. Ethical clearance was obtained from the Nepal Health Research Council.

**Results:** A total of 1009 (588 females) were enrolled in the study. Dementia was prevalent in 8.8% and 10.7% by Brief-CSID and IQ-CODE respectively. The bivariate analysis showed dementia was more frequent in ≥75 age group (OR 2.8[95% CI 1.9- 4.5]; p<0.001), having physical illness (OR 2.3[95%CI 1.3-3.9]; p=0.003), having hearing impairment (OR 1.9[95%CI 1.2-3.0]; p=0.004), and visual impairment (OR 1.9[95%CI 1.0-3.2]; p=0.023). Multivariate logistic regression analysis revealed dementia by Brief CSID was associated with ≥75 age group (AOR 2.296[1.418-3.719], p=0.001) and people using some form of mobility aids (AOR=2.022[1.19-3.435], p=0.009). Similarly, dementia by IQCODE was associated with illiterate groups (p=0.02) and homemaker by occupation (p=0.02). Functional impairment (EASI score ≥5) was present in 4.9%, and 19.5% had moderate disability by Barthel index.

**Conclusion:** The study showed the prevalence of dementia among people aged ≥60 years old is high and associated with the number of risk factors. Physical illness and sensory impairments may be a modifiable risk factor in this population.



# **Evaluation of the short version of the 10/66 Dementia Research Group diagnostic assessment for dementia in Arabic**

Prof Monique Chaaya<sup>1</sup>, Prof Khalil El Asmar<sup>2</sup>, **Ms Alexandra Abi Nassif Dit Hamouche**<sup>2</sup>

<sup>1</sup>American University of Beirut, Beirut, Lebanon. <sup>2</sup>American University of beirut, Beirut, Lebanon

# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Aims:** The 10/66 Dementia Research Group (DRG) diagnostic instrument is a reliable method for diagnosing dementia among Arabic-speaking older adults, including those with limited education. Nonetheless, its lengthy administration poses challenges for both participants and interviewers. This study evaluates the effectiveness of an abbreviated version of the 10/66 DRG in Arabic, focusing on its diagnostic accuracy relative to the standard version.

**Methods:** We used pre-existing data from 461 participants, aged 65 and above, originally collected for the validation of the standard 10/66 DRG. An algorithm for the abbreviated version was executed, and its outcomes were compared with the standard version for comparison. In the abbreviated version, the Geriatric Mental State (GMS) section is substituted by its shorter counterpart, the Euro-D.

**Results:** Statistical analysis using Cohen's Kappa indicated a strong concordance between the standard and abbreviated versions of the 10/66 DRG ( $\kappa$ =0.857)

**Conclusions:** The abbreviated 10/66 DRG appears to be a competent diagnostic instrument for detecting dementia in Arabic-speaking elderly populations in low- and middle-income countries. This is particularly beneficial for epidemiological studies where training time for interviewers is limited or where condensed interview durations are necessary. Specifically, the abbreviated version facilitates the inclusion of dementia diagnosis alongside other variables and research queries.



# Multimorbidity patterns and risk of mortality in hospital records among Chinese dementia patients

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# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Aims:** Multimorbidity has presented an increasing challenge to medical practice and a great burden on individuals, particularly those living with dementia. Few studies have assessed the association between multimorbidity patterns and mortality risk among Chinese dementia patients. We aimed to identify and compare multimorbidity patterns among patients with and without dementia and examine how these patterns were associated with all-cause mortality.

**Method:** Dementia patients diagnosed at 65+ between 2007 and 2017 were identified by International Classification of Diseases, ninth version (ICD-9) codes from electronic medical records from all public hospitals in Hong Kong. Each dementia case was 1:1 randomly matched with non-dementia patients who had no documented ICD diagnosis or prescription of anticholinesterases/memantine, based on age, sex and index date. Follow-up lasted until death or 31 Dec 2018. Latent class analysis was applied separately to identify multimorbidity patterns among all patients and patients with and without dementia for 59 chronic conditions. Cox regression was fitted for all patients to estimate hazard ratios (HRs) for risk of mortality associated with dementia, multimorbidity patterns and their interactions.

**Results:** A total of 156,710 individuals (mean age [SD]: 83.26 [7.28]; 40.4% males) with and without dementia was included. Eight multimorbidity patterns with clinical meaningfulness were obtained for all patients, among which the "metabolic and neurological diseases" pattern was independently associated with dementia risk. Among dementia patients, compared to "unspecific" pattern (with the least number of conditions), all other patterns showed a higher risk of mortality, particularly "clinically complex" [HR 1.94 (95% CI: 1.88, 2.01)], "respiratory" [HR 1.77 (95% CI: 1.69, 1.84)] and "heart" [HR 1.60 (95% CI: 1.55, 1.65)] patterns. The mortality risks were significantly higher among non-dementia patients in the same multimorbidity pattern.

**Conclusions:** Identification of older adults at specific multimorbidity pattern may improve decision-making and facilitate targeted interventions for dementia patients.



# Exploring urban and rural cognitive health disparities: A pilot comparative study in Kazakhstan with implications for MOCA testing

**Dr Aiym Kaiyrlykyzy**<sup>1,2</sup>, Dr Gulnaz Zholdassbekova<sup>3</sup>, Ms Aigerim Makhambetova<sup>1</sup>, Prof Sholpan Askarova<sup>1</sup>

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# **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Introduction:** Cognitive impairment in older adults poses a global public health challenge. The Montreal Cognitive Assessment (MoCA) is instrumental in detecting mild cognitive impairment, yet its adaptability to culturally diverse regions like Central Asia remains understudied. This research delves into MoCA's feasibility within Kazakhstan's small, diverse population, comparing urban and rural contexts. Understanding cognitive health disparities is crucial for tailored interventions.

**Methods:** Seventy-five participants, 52 urban and 24 rural residents from East Kazakhstan, underwent MoCA assessments by culturally aware professionals. Demographic data, including age and residence, were collected. The study documented challenges in administration, participant comprehension, and cultural adaptations. Statistical analyses and t-tests were used to compare MoCA scores between urban and rural participants.

**Results:** The study revealed no significant MoCA score differences between urban and rural participants. Despite the small sample size, the findings challenged assumptions about urban-rural cognitive disparities. Average MoCA scores were 22.9 in urban and 21.9 in rural areas. Ages averaged 67.8 years in urban settings and 65.7 years in rural areas. Due to the small sample, interpretation should be made with caution.

**Conclusion:** This research underscores MoCA's adaptability in urban and rural Kazakhstan, shedding light on cognitive health in an underexplored Central Asian context. The absence of significant MoCA score disparities between urban and rural participants emphasizes the necessity for larger-scale studies, particularly considering the limited dementia research in the Central Asian region, including Kazakhstan. Addressing these gaps is crucial for nuanced insights into cognitive health in Kazakhstan, guiding targeted interventions for the diverse aging population in this region.



# The ALFA3 pilot study: a unique cohort involving people living with Alzheimer's disease, and their first-degree relatives and caregivers

**Dr Kevin Rabiant**<sup>1</sup>, Dr Nicola Coley<sup>2,3</sup>, Prof David Wallon<sup>4</sup>, Dr Karim Bennys<sup>5</sup>, Mrs Gaelle Soriano<sup>2,6</sup>, Dr Pierre-Jean Ousset<sup>2</sup>, Prof Mathieu Ceccaldi<sup>7</sup>, Prof Sandrien Andrieu<sup>2,3</sup>, **Mrs Lorène Gilly**<sup>1</sup>

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### **Topic**

Dementia research and innovation: Epidemiology

### **Abstract**

Alzheimer's disease (AD) not only affects the life of the person living with the condition, but also their relatives. Currently, there is no cure for AD meaning that prevention strategies remain our most valuable assets. AD is preceded by a long preclinical period, during which changes in biological markers are detectable. Usually, they are measured through imaging or lumbar puncture, but reliable and less invasive blood tests are currently being developed, facilitating their measure. However, the data regarding these blood tests are still insufficient and it is not known how well blood markers predict the onset and progression of clinical symptoms. Furthermore, different modifiable factors as well as non-modifiable factors are potentially involved with AD risk. The interactions of all of these risk factors throughout the life course are yet to be fully studied. In this regard, it could be interesting to study such factors in first-degree relatives of people living with AD, since they present an increased risk of developing AD and may have greater motivation to participate in research studies. Finally, the impacts over time of supporting someone with AD deserve to be thoroughly studied, especially whilst studying in parallel the progression of their loved one's condition. In the pilot phase of the ALFA3 study, conducted in 3 French expert memory centres, in collaboration with the France Alzheimer Association, 150 family clusters (comprising a person living with Alzheimer's dementia, one of their care partners, and up to three first-degree relatives) will be recruited and followed-up for 2 years. The aim of this pilot phase is to study the feasibility of a larger scale study of prognostic and risk factors, including blood-based markers, in people with Alzheimer's dementia and their first-degree relatives, and the health, daily issues and needs of their care partners.





# Associations between Vascular Risk Factors and Clinical Parameters with Multimodal Brain MRI Indices: The LoCARPoN Study

**Dr Pallavi Nair**<sup>1,2</sup>, Dr Kameshwar Prasad<sup>3,2</sup>, Dr Parthiban Balasundaram<sup>4,5</sup>, Dr Deepti Vibha<sup>2</sup>, Dr Sada Nand Dwivedi<sup>6</sup>, Dr Shailesh B Gaikwad<sup>5</sup>, Dr Vivek Kumar<sup>6</sup>, Dr Achal Kumar Srivastava<sup>2</sup>

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#### **Topic**

Dementia research and innovation: Epidemiology

### **Abstract**

**Aim:** Dementia risk factors are well-established, but comprehensive evidence on the associations between multiple vascular risk factors (VRFs), their clinical parameters, and detailed brain MRI biomarkers in community-dwelling adults is limited, especially none from India. This study aimed to explore these associations and their impact on multimodal brain biomarkers.

**Methods:** LoCARPoN Study participants (N=401; 50-88 years) with VRFs (hypertension, diabetes, dyslipidemia, central obesity, >25kg/m2 body mass index, smoking, physical inactivity) and clinical parameters (increased systolicBP, hyperglycemia, impaired lipid profile, short sleep duration and elevated heart rate) were assessed. Brain MRI biomarkers included macrostructural, microstructural, and perfusion measures.

**Results:** VRFs such as central obesity, hypertension, and physical inactivity were found to be highly prevalent in our study participants, accounting for 73%, 66.1%, and 45.9%, respectively. Hypertension, central obesity, and diabetes were independently associated with all three brain measures (increased white matter hyperintensities (WHMs), lower perfusion, and higher white matter mean diffusivity; range |0.107| to |0.315|). Smoking was consistently associated with lower perfusion values and higher WMHs ( $\beta$  range |0.122| to |0.241|). High systolicBP showed a similar association like hypertension, additionally predicting lower white matter fractional anisotropy, unlike diabetes and hyperglycaemia. High BMI and LDL levels were associated with greater gray matter lobar atrophy, and elevated heart rate correlated with poorer white matter and higher perfusion measures. Dyslipidaemia, increased BMI, short sleepers, and physical inactivity did not show associations with any MRI markers. On Bonferroni correction (p=0.00018), all associations remained significant except for perfusion, warranting confirmation with longitudinal results.

**Conclusion:** Central obesity emerged as a notable risk factor in the Indian context. Similar associations were found between hypertension, diabetes, and smoking among Indians, consistent with global MRI findings. Despite small effect sizes, these results underscore the brain health vulnerability to VRFs in middle and older age, even in relatively healthy individuals.



# Possible crosslink between periodontal disease and Alzheimer's disease - the role of peripheral immune cells activation and response.

**Mr Michał Ochnik**<sup>1</sup>, Dr Maciej Sobczyński<sup>2</sup>, Dr Jacek Zborowski<sup>3</sup>, Dr Aleksandra Sender-Janeczek<sup>4</sup>, Prof Jerzy Leszek<sup>5</sup>, Prof Egbert Piasecki<sup>1</sup>, Dr Marta Sochocka<sup>1</sup>

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#### **Topic**

Dementia research and innovation: Epidemiology

### **Abstract**

**Background:** Alzheimer's Disease (AD) is the most common form of dementia in older adults. A wide range of processes that contribute to the disease-including inflammation, immune response, and participation of infectious agents are now explored. An association between AD and periodontal disease (PeD) - an oral infection caused by anaerobic bacteria of the subgingival biofilm (e.g. Porphyromonas gingivalis), was proposed. PeD may be an important source of systemic inflammatory molecules or bacteria toxic products that may influence systemic inflammation and the brain.

**Aims and Methods:** The aim of our research was to: (\*) investigate of the level of innate immune response of peripheral blood leukocytes (PBLs) ex vivo of patients with AD and PeD (test based on leukocyte resistance to viral infection) (\*\*) evaluate of the response of PBLs to stimulation with LPS derived from P. gingivalis (LPS-PG) by measuring pro- and anti-inflammatory cytokines, including: IFN- $\gamma$ , TNF- $\alpha$ , IL-1 $\beta$ , IL-2, IL-6, IL-10, IL -15 (Luminex) (\*\*\*) assess of the expression of inflammation-related genes in response to LPSPG stimulation: NFk $\beta$ , AP-1 (c-Jun), PI3KR1 p85, IRF3, IRF1, STAT1, STAT3, SOCS1, SOCS3, COX1, COX2 (RT-PCR). Sex-dependent differences in innate immune response of PBLs was also investigated.

**Results and Conclusions:** A comprehensive, multivariate statistical analysis of clinical, immunological and genetic parameters of 80 patients showed that the comorbidity of AD and PeD is associated with significant changes in the inflammatory response of peripheral immune cells. Our results suggest that PeD produces a systemic inflammation and finally may contribute of worsening neuroinflammation and progression of AD.





# Alzheimer and design: An exercise in raising awareness about the importance of spaces in a Brazilian setting.

Prof Tania Cristina Bordon Mioto Silva, Mr Paulo Alexandre Teodoro Grunwald Cokinos

Universidade Anhembi Morumbi, São Paulo, Brazil

# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

### **Abstract**

This summary focuses on understanding the specificities of spaces that accommodate people diagnosed with dementia, specifically Alzheimer's, through an architectural project in 2022, as part of the Undergraduate Project for the Architecture and Urbanism course at Anhembi Morumbi University in São Paulo, Brazil. The methodology explored healthcare spaces as an extension of the subjects' independence. For the design basis of this Care Center, the theoretical framework included books such as "Health of the Elderly" (ANDRADE FILHO, 1996), and "Third Age in Brazil: Representations and Perspectives" (SANTANA FILHO; COELHO, 2021). Other studies include the World Health Organization (WHO - 2020) and consultations with the websites of the Brazilian Confederations: FEBRAZ (Brazilian Federation of Alzheimer's Associations, since 1996) and ABRAZ (Brazilian Alzheimer's Association, since 1991). The confirmation that the pyramid of the elderly age group has been growing in Brazil, and the needs presented throughout the evolution of this condition have gone beyond the home, justifies the theme of the proposal. This exercise highlighted the need to study the relationship between humans and space concerning Alzheimer's: architecture is a necessary and effective tool for understanding this challenge, which significantly affects daily life. In conclusion, well-being and design encourage us to comprehend Alzheimer's and its relationship with the environment, personal interactions, and empowerment.



# Physical activity level of care partners does not directly influence the physical activity level of people with dementia.

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# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

Physical activity (PA) has been shown to be feasible and improve fitness, physical and cognitive function in people with dementia. Care partners can be pivotal in promoting PA participation for their care recipients and it is likely their PA levels impact on relevant decisions. The study examined the care partners' own PA levels and their perception of their care recipients' PA levels.

An online questionnaire was completed by care partners (n=452; age: 49.8±19.7 years, sex: males=165, females=287; care partner type: family member=324, professional=73), assessing their own PA levels and their care recipient PA levels (as the care partners perceived them), using the Rapid Assessment of Physical Activity (RAPA) questionnaire.

From those care partners that could estimate their care recipients' PA levels (n=336), just over half deemed their care recipients as active (n=180, 53.6%). The care partners scored their care recipients on RAPA as 2 (15.2%), 3 (18.2%), 4 (11.3%), 5 (3.3%), 6 (2.4%) and 7 (2.7%), a significantly different distribution between scores ( $\chi$ 2(5,178) =92.7, p<0.001). For care partners themselves, a significantly (p<0.001) higher percentage (n=258, 76.8%) to the respective care recipients' percentage was active. The care partners RAPA scores were 2 (12.2%), 3 (14.3%), 4 (17.0%), 5 (7.7%), 6 (5.5%) and 7 (14.3%) ( $\chi$ 2(5,255) =14.2.7, p<0.015). The care partners RAPA (4, IQR 3-6) scores were significantly different (Z=-7.0, p<0.001) to the care recipients' RAPA scores (3, IQR 2-4). Finally, the care partners' RAPA score showed significant but limited predictive ability of care recipients' RAPA scores (adjusted R2=0.221, F (1,151) =43.0, p<0.001).

Our results add to the literature examining care partners' and care recipients' PA levels and suggest that care partners' attitudes do not directly influence care recipients PA levels. Data directly obtained from care recipients and care partners should explore PA barriers and facilitators.





# Super Lingo - An Innovative foreign language program for cognitive training in older adults, Erasmus+ project.

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# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

# **Abstract**

Super Lingo, an innovative English language program, has emerged as a powerful tool for cognitive training in high-risk adults, including those with Subjective Cognitive Complaints (SCD), Mild Cognitive Impairment (MCI), and early-stage dementia. Rooted in research demonstrating the cognitive benefits of language learning, particularly in memory and attention enhancement, the program is not limited to specific age groups; it welcomes anyone eager to boost their cognitive abilities through English language acquisition.

The Super Lingo online application, comprising 18 English lessons, employs a variety of activities like vocabulary presentations, multiple-choice quizzes, card games, role plays, and jumbled sentences. To assess the program's impact, we monitored 188 participants from Romania, Slovenia, and Greece before and after the intervention. Divided into two groups, the participants engaged in regular Super Lingo sessions, lasting three to four months, with each session ranging from 10 to 15 minutes.

The outcomes were promising. Participants reported improved mood, reduced anxiety, and decreased internalized and external stigma. The perceptions of their quality of life did not differ significantly. Participants reported fewer negative stereotypes about being around other older adults making them feel inadequate. They felt more fulfilled and capable of learning, even in their later years. While challenges like irregular usage and device accessibility were identified, the overall response was positive. The Super Lingo methodology not only facilitated language learning but also significantly enhanced cognitive abilities, hinting at its potential for broader applications.

Funded by the European program Erasmus+, Super Lingo became accessible to the public in February 2022. Its intuitive approach, user-friendly interface, and positive impact on language skills and digital confidence have garnered praise. To learn more, visit the website http://superlingo.eu/en/ or reach out via email at info@alzheimerathens.gr.



# Building the Leaders of Tomorrow in Dementia Research and Advocacy: Multidisciplinary approaches from Poland

Ms Magda Kaczmarska<sup>1,2,3</sup>, Dr Rafał Nowak<sup>1,4</sup>, Dr Urszula Skrobas<sup>1,5</sup>

<sup>1</sup>Global Brain Health Institute, San Francisco, USA. <sup>2</sup>DanceStream Projects, New York, USA. <sup>3</sup>Foundation Dementia Action Alliance, Gdańsk, Poland. <sup>4</sup>Teknon Medical Center, Barcelona, Spain. <sup>5</sup>Medical University of Lublin, Poland

# **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

The Global Brain Health Institute (GBHI) constitutes a community of 230+ Atlantic Fellows for Equity in Brain Health from 50+ countries and leading faculty at University of California, San Francisco (UCSF) and Trinity College Dublin (TCD) engaged in a multitude of activities across research, practice, education, and advocacy to generate global impact in brain health through collective goals. GBHI takes a value-based approach to train and connect the next generation of leaders in brain health, science, arts, humanities and advocacy to reduce the scale and impact of dementia and drive change for millions of people globally. Poland is one of the fastest aging countries in the EU, with 9.8 million people >60 in 2020 and projections rising to 40% of the population by 2050. An estimated 1.5 million older persons in Poland are living with dementia. The actual number of people living with dementia in Poland is likely higher as dementia does not only affect older adults, even though age is the largest risk factor. To date, Poland lacks a National Dementia Plan to drive systemic cooperation between research, clinical practice and support. Despite trends among WHO and global leaders advancing lifelong brain health to promote risk reduction strategies, such public health approaches have yet to be implemented in Poland. Currently, three Atlantic Fellows for Equity in Brain Health are Polish nationals. In this presentation, neuro-imaging researcher, Rafał Nowak, neurologist, Urszula Skrobas and artist, Magda Kaczmarska, will share their ongoing work to advance the field of dementia and brain health research, practice and advocacy in Poland and beyond. They collectively represent a global network of progressive leaders who convene to exchange ideas, strategies, and inspiration for advancing brain health and dementia research, care, and advocacy. Together, they offer a message of hope and a call to action.



# P35-001

### LGBTQA+ and dementia

#### Mr Luca Croci

Colisée Italia, Milan, Italy

# **Topic**

Dementia research and innovation: LGBTQI+ and dementia

#### **Abstract**

According to an Ipsos poll carried out in 2023 in 30 countries, 4% of people who describe themselves as LGBTQA+ were born between 1948 and 1964.

Confirming the minority stress model according to which social stigmas and discrimination towards the LGBTQA+ population are at the root of mental health problems and inequalities in access to care, a study records that 15% of LGBTQA+ older people in the US are afraid to seek care outside their community. Furthermore, the fact that many older LGBTQA+ people have no or conflicting relationships with their biological family, have no children or live alone is an aggravating factor, as social isolation and loneliness increase the risk of dementia by 50%. Because dementia is a source of stigmatisation, it causes a further contraction of the social network, making it appropriate to speak here of intersectionality.

Dementia can alter cognitive skills in LGBTQA+ people, creating a violent loss of identity with involuntary coming out and outing, confusion in passing behaviour, and inconsistencies with the previous image of themselves. Caregivers must help the person to remain true to their gender identity by respecting their dress code or responding to specific care needs such as careful continuation of hormone therapy. Moving away from heteronormativity in dementia also means rethinking the notion of sexual misbehaviour, proposing activities that are not markedly gender-based, adopting both a patient-centred and a relationship-centred approach and finally changing the current narrative of healthy ageing that, by excluding LGBTQA+ people, fully contributes to their invisibility.



# P35-002

# When LGBTQ faces cognitive impairment

#### Ms Kublai Chiou

Taipei Veterans General Hospital., Taipei, Taiwan

# **Topic**

Dementia research and innovation: LGBTQI+ and dementia

#### **Abstract**

**Abstract:** LGBTQ is generally recognized as a cognitive problem. However, when this group reaches old age, will identity recognition also become an obstacle to determining cognitive impairment?

- 1. Is it memory confusion or cognitive impact?
- 2. Does memory trouble come from social pressure?
- 3. Lack of social inclusion for the LBGTQ group
- 4. Social equality in medical decisions
- 5. Both LGBTQ and cognitive disabilities are stigmatized, resulting in reduced living space?

LGBTQ people are originally a sexual orientation that is not recognized by the public. While they have fewer social resources, they are more likely to be affected by external pressure and identity, making it more difficult to receive appropriate care when suffering from dementia.



# P35-003

# Dementia, LGBT+, Intersectional Identities and the Assembly of Rights.

#### **Dr Clare Hammerton**

University of Essex, Essex, United Kingdom

# **Topic**

Dementia research and innovation: LGBTQI+ and dementia

### **Abstract**

Globally the number of people with dementia is estimated 55.2 million with 944,000 people currently diagnosed in the UK with this number projected to increase (Alzheimer's Research UK). There are no statistics on the number of Lesbian, Gay, Bisexual or Transgender (LGBT+) people with dementia in the UK, although people's experiences of dementia are affected by their identities.

The Alzheimer's Society UK identifies the specific needs and experiences of LGBT people living with dementia, carers, partners, and families of choice. Memory problems make it hard for people to remember who they have told and who they want to tell about their sexual orientation and gender identity. People accessing care may be in contact with people displaying micro-aggressions and non-affirmative behaviour, even though they are protected and recognised by UK legislation. Memories of prejudice, discrimination, and hate crimes can cause distress with negative attitudes, rejection, abuse, hostility and complicated relationships with families, all affecting people's experiences of living with dementia.

This research recruits LGBT+ people and carers living with dementia to talk about their experiences of support and services. It will collate knowledge on experiences, analyse themes, and share to effect change in Health and Social Care knowledge and delivery. Focusing on sexual orientation and gender identity it will use an intersectional lens layering age, gender, disability, ethnicity and other identities experiencing health inequalities to identify how mainstream support and services are, or are not, structured to respond to identity-related needs and experiences.

Through a Rights-Based approach to research, this research will build opportunities for participants to gain collective support, present their experiences of Health and Social Care, create knowledge exchange, grow their voice, and grow their capacity as Expert Experienced researchers to lead to the assembly of rights for LGBT+ people and carers living with dementia.



### Killifish as a new model for Alzheimer's disease

#### Miss Yilin Zhang

University College London, London, United Kingdom

# **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

As the world's population ages, the prevalence of age-related diseases, notably Alzheimer's disease (AD), is on the rise, negatively impacting the quality of life. AD is a neurological condition characterized by a gradual decline in cognitive function. Unfortunately, we currently lack effective treatments for AD due to challenges in research.

One significant challenge is the absence of suitable disease models. Existing laboratory animal models do not naturally develop AD, and traditional studies using transgenic animals are costly and time-consuming. To overcome this hurdle, scientists are exploring the African turquoise killifish (*Nothobranchius Furzeri*), a species with a short lifespan and aging traits like humans.

Our project aims to investigate whether laboratory-reared killifish can develop AD spontaneously. This involves a comprehensive analysis of key AD-related proteins, tau and beta-amyloid (AB), in aging killifish brains, alongside monitoring inflammatory markers.

By utilizing the rapidly aging killifish brain as a model, we seek insights into the cellular and molecular processes driving AD within vertebrate central nervous systems. Successful outcomes could pave the way for target validation and drug discovery in killifish, advancing our understanding of healthy aging and AD treatment development.



# Alzheimer's & Design: An exercise in raising awareness about the importance of spaces in a Brazilian setting.

Prof Tania Cristina Bordon Mioto Silva, Mr Paulo Alexandre Teodoro Grunwald Cokinos

Universidade Anhembi Morumbi, São Paulo, Brazil

# **Topic**

**Dementia research and innovation:** New and future approaches and treatments

### **Abstract**





# Electroacupuncture could balance the gut microbiota and improve the learning and memory abilities of Alzheimer's disease animal model

Prof Jing Jiang, Miss Xiaoyue Zhao

Beijing University of Chinese Medicine, Beijing, China

# **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

Alzheimer's disease (AD), as one of most common dementia, mainly affects older people from the worldwide. In this study, we intended to explore the possible mechanism of improving cognitive function and protecting the neuron effect by electroacupuncture.

**Method:** We applied senescence-accelerated mouse prone 8 (SAMP8) mice as AD animal model, used Morris water maze, HE staining, 16S rDNA amplicon sequencing of gut microbiota and ELISA to demonstrate our hypothesis.

**Results:** electroacupuncture improved the learning and memory abilities in SAMP8 mice (P<0.05) and could protect the frontal lobe cortex and hippocampus of SAMP8 mice; electroacupuncture significantly decreased the expression of IL-1 $\beta$  (P<0.01), IL-6 (P<0.01) and TNF- $\alpha$  (P<0.01 in hippocampus, P<0.05 in serum) in serum and hippocampus; electroacupuncture balanced the quantity and composition of gut microbiome, especially of the relative abundance in Delta-proteobacteria (P<0.05) and Epsilon-proteobacteria (P<0.05).

**Conclusion:** electroacupuncture treatment could inhibit the peripheral and central nerve system inflammatory response by balancing the gut microbiota.



# Investigating the therapeutic potential of targeting NKCC1 and KCC2 dysfunction in Alzheimer's Disease

**Dr Andrea Kwakowsky**<sup>1,2</sup>, Miss Patricia Lam<sup>2</sup>, Dr Beatriz Calvo-Flores Guzmán<sup>2</sup>, Miss Julia Newland<sup>2</sup>, Dr Katie Peppercorn<sup>3</sup>, Prof Warren Tate<sup>3</sup>, Prof Henry Waldvogel<sup>2</sup>, Prof Richard Full<sup>2</sup>

<sup>1</sup>University of Galway, Galway, Ireland. <sup>2</sup>University of Auckland, Auckland, New Zealand. <sup>3</sup>University of Otago, Dunedin, New Zealand

# **Topic**

**Dementia research and innovation:** New and future approaches and treatments

# **Abstract**

Alzheimer's disease (AD) is a neurodegenerative condition. The inhibitory  $\gamma$ -aminobutyric acid (GABA) neurotransmitter system undergoes remodelling in AD, thus disrupting the excitatory and inhibitory (E/I) balance in the brain. The cation chloride-cotransporters, K-Cl-2 (KCC2) and N-K-Cl-1 (NKCC1), have been implicated in several neurological disorders as they affect GABA signalling polarity, but have not been explored in AD. This study examined the potential neuroprotective effects of bumetanide, an NKCC1 inhibitor, in an AD mouse model. Primary mouse hippocampal cultures were treated with beta-amyloid (A $\beta$ 1-42) and bumetanide (1 $\mu$ M, 10 $\mu$ M, 100 $\mu$ M, 1mM) to investigate the effect of bumetanide on cell viability. A $\beta$ 1-42 produced 53% cell death after 5 days, which did not improve with bumetanide treatment. Bumetanide at 1 $\mu$ M alone, and at higher concentrations, leads to 61.5 ± 1.2% cell death after 5 days, suggesting bumetanide is neurotoxic. No change in KCC2 and NKCC1 expression was observed in the in vitro AD model, however, localized NKCC1 upregulation and KCC2 downregulation were apparent in the CA1 subregion of the hippocampus in an in vivo AD mouse model. This research is questioning bumetanide's suitability for AD therapy and suggests that further investigations are required to examine whether targeting KCC2/NKCC1 might offer a therapeutic approach for AD.



# Investigating Relative PSD Difference and Coherence Analysis in rEGG of Alzheimer's Disease

Mr Chanda Simfukwe, Dr Young Chul Youn

Department of Neurology, Chung-Ang University College of Medicine, Seoul, Korea, Republic of

# **Topic**

**Dementia research and innovation:** New and future approaches and treatments

### **Abstract**

**Objective:** Electroencephalography (EEG) is a valuable non-invasive technique for comprehensively assessing the electrical activity of the brain's cerebral cortex. In this study, EEG was employed to investigate potential neuropsychological biomarkers in detecting varying stages of Alzheimer's disease (AD) through quantitative EEG (qEEG) analysis of resting state EEG (rEEG) signals under eyes-open (EOR) and eyes-closed (ECR) conditions. Abnormalities in rEEG signals were compared between AD patients and normal controls using 19-scalp electrode EEG signals.

**Methods:** The study analyzed rEEG data from 534 subjects aged 40-90, comprising 269 normal and 265 AD subjects in Korea. Quantitative EEG analysis for EOR and ECR states was conducted separately for normal and AD subjects to measure relative power spectrum density (PSD) and coherence, evaluating abnormalities. Data preprocessing and analysis were performed using EEGlab and Brainstorm toolboxes in MATLAB R2021a, with statistical analyses conducted via ANOVA.

**Results:** The analysis, employing the Welch method, revealed increased relative PSD in the delta frequency band across 19 EEG channels, particularly in the frontal, parietal, and temporal regions in the AD group compared to normal, demonstrating a significant difference. Delta power band at the source level was increased in AD but decreased in normal. Moreover, activities in alpha, beta, and gamma frequency bands were significantly reduced in the AD group, notably the beta frequency band in all brain areas. Coherence analysis demonstrated a remarkable increase in pair-wise coherence between different brain areas in the AD group during the ECR state, with subsequent reduction after subtracting the EOR state.

**Conclusion:** The study indicates that analyzing PSD and functional connectivity through coherence analysis provides a promising and comprehensive approach to differentiate individuals with AD from normal controls. This approach holds the potential to enhance our understanding of AD by offering valuable insights into disease progression and aiding in early detection and monitoring.





# P36-007

# Dutch Dementia Research programme: joining forces for a world without dementia

Miss Daniëlle van Spijker, Miss Gabriëlle Lijten

ZonMw, The Hague, Netherlands

### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

### **Abstract**

In the Netherlands, ZonMw's <u>Dementia Research Programme</u> (2021-2030) aims to bring synergy and focus to the dementia field. This is accomplished by multidisciplinary collaboration between parties active in research, education, healthcare, and with experts by experience. The programme is committed to knowledge development and the transfer, upscaling and broad utilisation of knowledge and innovations. It aims to contribute to the prevention of dementia and to a better quality of life for people with dementia and their loved ones, now and in the future.

In the course of ten years, 140 million euros is allocated in a phased approach. The programme strategy consists of three core components:

The work packages (WP) that determine the direction and focus of the programme:

- Fundamental Research
- Risk Reduction
- Diagnosis (and Prognosis)
- Promising Innovative Therapies
- Early Onset Dementia
- Knowledge Transfer: Integration of Education, Research and Care

Incentivising and facilitating a high-quality knowledge, research and development infrastructure, through forming large-scale multidisciplinary partnerships (research consortia). To date, five multidisciplinary consortia within WP 1,2,3 and 5 were funded as well as the overarching WP6 consortium.

Programming and funding of research calls, including consortia grant calls, open fellowship calls, implementation calls, demand-driven calls (e.g. driven by policy priorities), and Dutch participation in grant calls organised by the global <u>Joint Programme – Neurodegenerative Disease Research</u> (JPND).

The Dementia Research Programme is part of the Dutch Ministry of Health, Welfare and Sport's National Dementia Strategy (2021-2030) and is dedicated to one of its three main themes: 'A world without Dementia'. *Alzheimer Nederland* is a partner of the programme.



# P36-008

# Change Management of Neurocognitive Disorder in Veneto Region-Italy: the Three-Year Activity Plan (2021-2023) - Alzheimer's and Dementia ministerial fund

**Dr Cristina Basso**<sup>1</sup>, Dr Marco Simoni<sup>1</sup>, Dr Silvia Netti Tiozzo<sup>1</sup>, Dr Donata Gollin<sup>2</sup>, Dr Alessandra Zapparoli<sup>3</sup>, Dr Pierangelo Spano<sup>3</sup>

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## **Topic**

**Dementia research and innovation:** New and future approaches and treatments

### **Abstract**

In the field of neurocognitive disorders (NCD), scientific advances and innovative approaches to overcoming the "silo approach" and fragmentation of care depict a major organizational challenge for the healthcare system. In this context, it is a matter of priority to meet the changing health needs of the person with a neurocognitive disorder, by promoting appropriate, continuous, and sustainable access to health care over time. The Three-Year Activity Plan - Alzheimer's and dementia ministerial fund - has allowed the Veneto Region to strengthen an organizational infrastructure for the implementation of total care of the person from the early stage of the disease, by promoting rehabilitation as a therapeutic opportunity in which the person is the active protagonist of their path.

### The Three-Year Activity Plan had the following main objectives:

- updating of the mapping of the rehabilitation offer for people living with dementia;
- staffing and training of clinical centers' dedicated professionals;
- planning rehabilitation activities and their implementation through specific software;
- telerehabilitation pathway activation in the clinical centers' regional network;

The project involved 11 clinical centers, recruiting and strengthening the dedicated staff (psychologists and speech therapists) and adequating their Information Technology including a software to standardize the rehabilitation path. The skills of cognitive telerehabilitation have been regionally harmonized by continuous training.

The rehabilitation proposals, the multidisciplinary integration, and synergy with the territory have strengthened the regional model of taking care of the person with NCD, generating a harmonious and shared cultural heritage in the clinical centers involved throughout the Veneto Region. The high adherence to the project and the constant sharing and dialogue between the professionals, combined with the positive assessment coming from participants, care partners, and professionals have resulted in a unanimous request for the continuation of this project.





# Improvement of working memory in older adults with Mild Cognitive Impairment after repetitive Transcranial Magnetic Stimulation – a randomized controlled effectiveness study

Ms Adrianna Helena Senczyszyn<sup>1</sup>, Prof Joanna Rymaszewska<sup>2</sup>, Prof Dorota Szcześniak<sup>1</sup>

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### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

## **Abstract**

**Aims:** Repetitive transcranial magnetic stimulation (rTMS) is a noninvasive technique that could improve cognitive function. It is being developed as a non-pharmacological intervention to alleviate symptoms of cognitive deterioration. The study assesses the efficacy of rTMS in improving cognitive functions in MCI patients. Furthermore, we wanted to investigate, if combining rTMS with computerized cognitive training enhances the efficacy of rTMS.

**Method:** We assessed the efficacy of rTMS in improving cognitive functioning among people with Mild Cognitive Impairment (MCI) in a double-blinded, sham-controlled randomized trial. Out of 91 subjects screened, 31 participants with MCI were randomly assigned to one of three groups: (A) Active rTMS; (B) Active rTMS with Computerized Cognitive Training RehaCom; and (C) Sham control. The study evaluated cognitive function using the DemTect, FAS, and CANTAB tests before and after the stimulation. The following treatment protocol was applied: 2000 pulses at 10 Hz, 5-s train duration, and 25-second intervals at 110% of resting MT delivered over the left Dorsolateral Prefrontal Cortex (DLPFC) five times a week for two weeks.

**Results:** After 10 sessions of high-frequency rTMS, there was an improvement in overall cognitive function and memory, assessed by the DemTect evaluation, with no serious adverse effects. Analysis of differences in time (after 10 sessions) between studied groups showed statistically significant improvement in DemTect total score (time by group interaction p=0.026) in favor of rTMS+RehaCom. The linear regression of CANTAB Paired Associates Learning revealed substantial differences in favor of rTMS+RehaCom in three subtests.

**Conclusions:** Our study shows that 10 sessions of rTMS over the left DLPFC (alone and combined with Computerized Cognitive Training) can positively impact cognitive function in people with MCI. Further research should investigate the underlying mechanism and determine the optimal parameters for rTMS, which will be necessary for its efficacy in clinical settings.



# The Effectiveness of Self-Management Program on the People Living with Dementia in the Community

**Prof Hsiu-Li Huang**<sup>1</sup>, Dr John Sai-Hung Tang<sup>2</sup>, Prof Yang-Tzu Li<sup>1</sup>, Miss I-Hsuan Tung<sup>2</sup>, Mr Yu-Sheng Cheng<sup>2</sup>, Mr Chun-Yu Chen<sup>2</sup>

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## **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

**Aim:** To evaluate the effectiveness of self-management program on the people living with dementia in the community.

**Methods:** The research team developed a self-management program specially designed for people living with dementia after 6 expert meetings and 2 group trials. The content of the program includes a total of 15 times, including "cultivating healthy living habits", "improving self-efficacy", "reducing the impact of disease progression on daily life", "community connection", "family interaction and communication", and "advance care planning". Once a week, 2 hours each time. The single-group pre- and post-tests design was used that a total of 82 people with mild dementia participated self-management programs in the 9 community centers. The scales of self-efficacy, exercise days, and depressive symptoms were tested before and after the program.

**Results:** A total of 70 people living with mild dementia completed the pre- and post-tests. The average scores of the pre-tests were self-efficacy (27.12 $\pm$ 8.07), exercise days (4.34 $\pm$ 1.84) and depressive symptoms (1.71 $\pm$ 2.49), respectively. The posttest mean scores were self-efficacy (29.83 $\pm$ 9.03), exercise days (4.91 $\pm$ 1.85) and depressive symptoms (1.23 $\pm$ 2.50), and the paired-t (p values) were -2.95 (p=0.004), -3.27 (p=0.002), 2.37 (p=0.021), respectively.

**Conclusions:** People living with mild dementia are able to participate in self-management. Preliminary results show that self-management programs can help people with dementia improve self-efficacy, exercise frequency and reduce depression. It is suggested that self-management programs can be promoted in community dementia care centers.



# **Broaden Knowledge About Dementia Through Reading Social Prescriptions**

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# **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

### **Purpose:**

Through cooperation with libraries on reading prescriptions, we hope to increase the public and dementia family members to use public resources, strengthen dementia awareness, initiate active learning, and achieve the Sustainable Development Goals (SDGs) proposed by the United Nations of Good Health and Well-Being goals in.

**Method:** The dementia reading prescription promotion model consists of three parts:

- 1. Organize a "book club" where professional medical staff recommend a book on dementia care and let family members read it, and then the professional staff will lead the book club. During the reading group, lead family members to share their experiences or discuss areas where they have doubts while reading.
- 2. Professional medical staff collect books related to dementia in the library, recommend suitable books, and publish them on the website of the Taipei Municipal Library Main Library; the Dementia Center of Taipei City Hospital also links to recommended websites for dementia books are promoted to dementia family members, including: LINE groups and FB social media, allowing more families with dementia and the general public to benefit from libraries as a public resour.
- 3. Carry out dementia education and training for library volunteers: Provide initial and advanced dementia education and training for library volunteers. The content of the initial course includes: understanding of dementia, warning signs of dementia, etc.; the advanced course allows volunteers to actually have face-to-face conversations with people with dementia, allowing volunteers to understand how to communicate and interact with people with dementia. STE2P skills (Smile, Thanks, Eye contact, Embracing the moment, Patience), through the course, understand what are the correct interactive communication skills for dementia.

**Result:** This time, there were three sessions of reading prescriptions for dementia, a total of 9 courses, with a total of 97 participants, and the overall satisfaction rate was 97.3%.



# Effectiveness of EEG-based Cognitive Training in Older Persons: A Rapid Review

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### **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

EEG-based cognitive training (CT) is a promising treatment modality for persons living with dementia that combines traditional cognitive rehabilitation with EEG neurofeedback.

This review aimed to evaluate the effectiveness of EEG-based CT in improving cognition in older persons as measured by the following quantitative batteries of tests—(1) Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), (2) Modified Mental Status Examination (MMSE), (3) Montreal Cognitive Assessment (MoCA), (4) NeuroTraxTM, and (5) Wechsler Adult Intelligence Scale III (WAIS-III).

We performed a search on PubMed based on keywords and performed a hand search through article references for potentially relevant articles for randomized control trials (RCTs), systematic reviews and meta-analyses. A total of 11 articles were analysed based on the 5 batteries of tests.

3 articles showed effectiveness (1 for RBANS, 1 for MMSE, 1 for NeuroTraxTM). EEG-based CT was found to be effective particularly in Chinese-speaking older persons without dementia in the RBANS study where an increase of 0.5 (Range -10 to 29, p= 0.042) was seen in the median RBANS total index score, and Korean persons living with dementia in the MMSE study, an increase in mean MMSE- K scores by 2.67 from  $19.53\pm1.30$  to  $22.20\pm1.15$  (p<0.001) .The role of education level and pre-test cognitive abilities were elicited as reasons for such a response, describing a ceiling effect. Furthermore, some studies demonstrate improvement in some cognitive domains (such as immediate verbal and non-verbal memory) and not in others.

Our study revealed heterogeneity not only in the cognitive outcome measures used to evaluate EEG-based CT but also in its effectiveness in older persons. More robust research is needed to evaluate the potential benefits in relation to ethnicity, education level, and severity of cognitive impairment and dementia.



# Virtual Cognitive Stimulation Therapy (vCST) and carer support: Participatory gerontechnology, effectiveness, cost-effectiveness, and mechanisms

### **Dr Gloria Wong**

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## **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

**Aims:** Group-based cognitive stimulation therapy (CST) is recommended for enhancing cognition and quality of life in people with dementia. Having an online delivery option may improve its accessibility. It also allows examining mechanisms using videotaped behavioural data in therapeutic sessions. This ongoing study aims to design and evaluate a protocol of virtual CST with carer support and identify mechanisms leading to clinical benefits.

**Method:** We involved 45 people with dementia, carers, and CST facilitators in a co-design process of an experimental vCST protocol. A total of 156 dyads of people living with dementia and their carers will be randomly allocated to receive in-person or online CST and carer support. Using random time sampling, we identified 5-minute video clips to annotate multimodal behavioural markers of the sessions as outcome predictors and used machine learning methods to discover intervention mechanisms.

**Results:** Design ideas generated from the participatory gerontechnology process highlighted the need to enhance person-centredness and engagement. A web-based portal is developed to facilitate access to vCST and online carer support. The ongoing cluster randomised trial has recruited 108 dyads: baseline cognitive performance of the person with dementia is  $19.2 \pm 8.7$  on ADAS-Cog and quality of life is  $27.2 \pm 4.8$  on QoL-AD. Using pilot video data from vCST sessions, an eye fixation pilot training study shows that behaviours captured on computer cameras during online therapy sessions can be automatically estimated reliability, with eye fixation measured using deep learning methods potentially applicable as a behavioural marker. Other target behavioural markers including person-centred speech and wellbeing are being developed.

**Conclusions:** Internet-delivered interventions can be co-designed with people with dementia and their carers. Findings from this study will inform the effectiveness and cost-effectiveness of this participatory gerontechnology and the potential of behavioural markers generated from such technologies to advance non-pharmacological interventions.



# hAlt - An Erasmus+ Sport educational and training programme for older adults at risk of developing dementia through table tennis.

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## **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

Erasmus+ is the EU transitions and support education, training, youth, and sport in Europe, with currently a budget of ~€26 million and a strong focus on social inclusion, the green and digital transitions, and promoting young people's participation in democratic life. Funding opportunities under Erasmus+ include Sport actions, designed to tackle societal and sport-related challenges.

A funding proposal with the aim to explore the use of table tennis as a means of physical activity for older people at risk of developing mild cognitive impairment and dementia was submitted in April 2020 with notification of the successful outcome in October 2020. The proposal consisted of 10 partners from six different countries. The choice of table tennis as the means of promotion of physical activity in older people at risk of developing dementia was made on the basis of the interactive (with the carer) nature of the sport as well as the concurrent physical and cognitive demands and development of the respective attributes. The premise was to understand the current evidence around the topic, obtain the views of carers and people living with dementia, create a platform for an online community and wearables for monitoring, and finally a trainer certification programme leading to the intervention (training programme). The project achieved the deliverables as described in the proposal, as well as additional 'value for money' outputs. Currently the pilots are running and will be completed in December 2023.

The insights and knowledge gained throughout the entire process, from submission to completion, can be valuable resources for colleagues. These reflections and lessons learned can guide them in their own submissions and enable them to apply the program's methodology to future proposals involving different clinical populations.





# The Nexus program - an evidence-based specialized brain health program focusing on person-centered care practice meeting physical, social, and emotional needs

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### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

## **Abstract**

**Background:** The ADI-accredited Dementia Specialist education and training program at Silverado is based within a non-medical residential memory care model with an approach to care designed to meet whole-person needs; physical, social, and emotional: The Nexus program. Over the past 27 years, the foundational philosophies of dignity with risk, normalization, living with purpose and building social connections through robust, individualized brain healthy programming has led to a reduction of excess disability, and improvement in clinical outcomes. Similar results have been obtained within a Danish pilot following implementation in eight Danish nursing homes so far.

**Methods:** The Nexus program is focused around 5 pillars of brain health: physical activity, purposeful social activities, stress reduction, cognitive exercises, and a participant support group. Residents receive regular assessments of cognition, functional status, mood, and behavior. During 2019-2021, 400 Danish staff-members and 375 nursing home residents was designed as a 6-month action learning-based competence-lift containing knowledge and skills in working with the 5 pillars and in building on successes and add awareness and systematics to their work.

**Results** The Danish results showed positive changes in both resident's well-being and in staffs job satisfaction. Focus group-interviews with staff before and after the implementation process revealed a decrease of sedative and sleeping medication, increased appetite, coziness at meals, better sleep and making friendship. Generally, residents' physical and cognitive abilities increased.

For the residents with a mild to average MMSE score at baseline, 83% of increased their MMSE score with 5.05 point and their Barthel score with 85%.

**Conclusions** The Nexus approach provides those living with dementia the same patterns and conditions of everyday life that are common for those who are not cognitively impaired. Staff members are encouraged to not just care for, but to care about the residents.



# Optimising psychosocial interventions in care-homes through Bayesian power analysis

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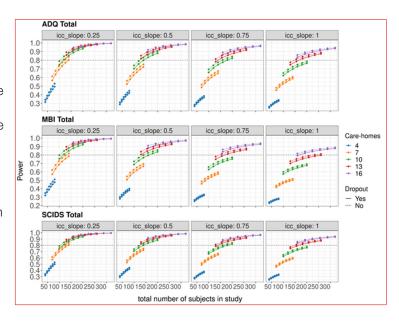
## **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

**Aims:** We conducted a power analysis in a field design with seven care-homes in Mexico City, using as outcome variables the total scores of the staff in the Maslach Burnout Inventory (MBI), the Approaches to Dementia Questionnaire (ADQ), and the Sense of Competence in Dementia Care Staff (SCIDS), with the aim of improving the optimality of this type of psychosocial intervention.

**Methods:** The study included measurements before the intervention (baseline), 12 weeks after the intervention (post-intervention), and after 24 weeks (follow-up). These three time points were used to model the rate of change in the response variable (i.e., intervention-time interaction) between individuals and between care-homes in a three-level nested design. Information on the distribution of variables (mean ± SD of intervention at baseline) in our study and in a study Moniz-Cook et al. (2017) were implemented in a Bayesian framework and posterior simulations to compare our design with designs involving larger numbers of subjects and/or



care-homes across intervention phases and with different values of variance-related parameters, including intraclass correlation of the growth curves from baseline to follow-up, variance ratio, and a standardised Cohen's d index. We also consider dropout rates.

**Results:** Our design achieved near-median power values for the rate of change (intervention × time) for the total outcome variables ADQ (52%), MBI (42%), and SCIDS (50%). However, the overall effect of our design was generally smaller for all three outcomes, and a design with 10 care-homes and 100 to 150 subjects was sufficient to achieve power above 80%. Increasing the variance between subjects and/or the number of subjects or homogenising the variability between care-homes would also result in better power for ADQ and MBI.

**Conclusion:** This analysis demonstrates the importance of sample size, between-individual variability, and between-care home variability on the effects of psychosocial interventions.



# A Multidisciplinary approach in the development of a co-designed innovative telerehabilitation intervention for People living with Dementia in Veneto Region (Italy)

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## **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

Through the Three-Year Activity Plan (2021-2023), a project supported by the Alzheimer's and dementia ministerial Fund, the Veneto Region had the opportunity to implement, evaluate, and diffuse an innovative telerehabilitation intervention for people with neurocognitive disorders within 11 clinical centers.

The project's aim is to drive cultural change through the promotion and dissemination of remotely delivered rehabilitation involving people with neurocognitive disorders in the co-design process and in the software's usability evaluation, with the support of a multidisciplinary team.

### The Three-Year Activity Plan (2021-2023) allowed:

- the acquisition and inclusion in the multidisciplinary team of new psychologists and speech therapists within the clinical centers
- the realization of a training course addressed to the professionals involved in the project
- the involvement of people with dementia in the co-design process and in the software's usability evaluation
- the activation of 8 weeks' telerehabilitation pathways
- the creation of Usability Working Groups involving people living with dementia
- multidisciplinary team coordination: psychologists, speech therapists, and all rehabilitation, health- and social-care professionals, persons living with dementia worked together on an integrated approach

The Three-Year Activity Plan allowed the diffusion of a rehabilitation culture based on a multidisciplinary and integrated approach, and on the direct involvement of the person in the planning of their telerehabilitation pathways.

The multidisciplinary approach brought together a range of professionals that ensured that all the specific needs and resources of the person were taken into account when planning personalized and appropriate intervention.

This approach provided more knowledge and experience contributing to strengthening and spreading the rehabilitation offer and a person-centered rehabilitation culture throughout the Region.

Promoting a culture that includes individuals with lived experience in the co-design of interventions brings unique knowledge and experience to the whole process and represents an essential good practice within the multi-professional team.



# Effects of creative expression program on patients with mild cognitive impairment: based on Transcranial Doppler ultrasound

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## **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

**Aims:** In this study, patients with mild cognitive impairment (MCI) were treated with the creative expression program (CrExp) and assessed for changes in cognitive function, while the correlation between changes in cognitive function and cerebral hemodynamic parameters was explored based on Transcranial Doppler (TCD) ultrasound.

**Method:** CrExp intervention was implemented in 35 participants for a total of 24 intervention sessions lasting approximately 0.5-1 hour each over 24 weeks. All participants underwent a pre-and post-intervention MoCA assessment. And their cerebral hemodynamic parameters were measured by TCD ultrasound before and after the intervention.

**Results:** After the intervention, MCI patients treated with CrExp had significantly higher cognitive function scores than before the intervention (MoCA; t=-2.15, P=0.036). TCD parameter measurements showed that the mean blood flow velocity and the resistance index values of the vertebral artery, the basilar artery, and the middle cerebral artery in MCI patients were significantly lower than the normal mean (P = 0.05), while the pulsatility index values of the vertebral artery and the middle cerebral artery were significantly higher than the normal mean(P = 0.05). Mean blood flow velocity in the middle cerebral artery was positively correlated with changes in cognitive function, whereas RI was negatively correlated with changes in cognitive function(P = 0.05).

**Conclusions:** This study provides evidence that TCD ultrasound can provide an objective basis for the diagnosis of mild cognitive impairment and can be tested by TCD ultrasound to determine the correlation between the effect of the cognitive intervention and changes in hemodynamic parameters.



# Tailoring leisure activity interventions in adult day services - Development of a preference instrument using cognitive interviews

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# **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

**Background:** Adult day services are an important care environment for people with dementia and offers various leisure activities. These activities are often based on the conditions or needs of the people receiving ADS, rather than their preferences. However, tailoring leisure activity interventions based on preferences is critical for meeting the psychological needs for competence, autonomy, and relatedness, and thus addressing the well-being and personal growth of people receiving ADS. So far, no instrument exists for a comprehensively assessment of preferences for leisure activities of people receiving ADS.

**Methods:** We developed together with people receiving ADS an instrument for the assessment of these preferences. Based on a concept mapping, we identified 12 clusters of preferences for leisure activities and adopted the structure of the Preferences for Everyday Living Inventory (PELI). In accordance with this structure, we phrased our cluster labels as questions, adopted the importance rating scale of the PELI, and developed a first draft of the Preferences for Leisure Activities Inventory (PLAI), which was critically reflected and commented by the research team. Furthermore, these comments were evaluated using cognitive interviews with people receiving ADS to revise, validate, and finalize the PLAI.

**Results:** Our first draft of the PLAI included 25 different questions. After one round of cognitive interviews (n = 8), the number of questions was reduced to 21, and 3 questions were rephrased. Furthermore, based on the response processes of the people receiving ADS validity for the PLAI could be provided.

**Conclusion:** The PLAI is the first instrument available to health professionals in the ADS environment to assess the preferences of leisure activities of people receiving ADS and provides the basis for tailored leisure activity interventions based on preferences.



# Cultivating Intergenerational Conversations: Tapping into Seniors' Wealth of Experience through Museum Artefacts and Stories

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### **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

Since 2014, NTUC Health and My First Skool's Inter-Generational (IG) programme has brought children and seniors together to share experiences, learn alongside each other and develop relationships within the senior day centres. The IG programme provides seniors with opportunities to express generativity - allowing them to pass down their wisdom, experiences, and cultural heritage to younger generations.

Due to the pandemic, face-to-face activities with children were halted. Maintaining engagement between seniors and children is essential, especially during a time of isolation. Adapting to the challenges, the senior day centres sought to collaborate with like-minded partners to pilot virtual IG activities. One such activity was a virtual heritage-based IG programme co-developed with the National Museum of Singapore (NMS), culminating in a showcase of artworks created by seniors and children that was displayed for the latter's Children Season in 2021.

This pilot activity conducted since 2021 leverages NMS' artefacts to foster IG conversations through virtual tours guided by NMS' volunteers. During the tours, there were opportunities for seniors to share their life stories and experiences with the preschoolers as they viewed the artefacts and preschoolers learnt what life was like for seniors growing up in the past. Thereafter, preschoolers were invited to ask seniors questions through an exchange of Pen Pal cards, and they engaged in artmaking together to create artworks inspired by the artefacts and their conversations.

A total of 156 seniors participated in the pilot programme, including 49 persons living with dementia. Based on the feedback collected, 95.5% of seniors expressed interest in participating in similar programmes again. Seniors highlighted that engaging in conversations with children and sharing their life experiences filled them with profound sense of pride. A notable proportion of seniors voiced their desires to visit the museum physically and expand their knowledge of museum artefacts too.



# Prescription of Non-Pharmacological Interventions in Memory Clinics: Data from the Clinical Pathway for Alzheimer's Disease in China (CPAD) Study

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### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

**Aims:** Nonpharmacological interventions are recommended to improve outcomes in dementia. Little is known about their prescription in practice, especially in non-western populations. We investigated individual- and institution-level characteristics associated with non-pharmacological intervention prescription in China.

**Method:** This study employed cross-sectional data from 889 community-dwelling outpatients living with dementia aged ≥45 years from a multicentre registry of 28 memory clinics in China. Prescription records, carer and clinic characteristics, and reasons for declining non-pharmacological intervention were collected. Multilevel logistic regression was used to identify factors associated with non-pharmacological intervention prescription.

**Results:** Non-pharmacological interventions were prescribed in 323 (36.3%) of people with mild cognitive impairment or dementia. Cognitive activities and carer training/support were the most prescribed interventions. Multilevel logistic regression showed that 73% of the variance in prescription were attributed to institutional characteristics of the memory clinic. Greater caregiving gain (OR 1.06, 95% CI 1.02-1.09), lower burden (OR 0.97, 95% CI 0.94-0.99), worse carer-perceived dyad relationship (OR 0.83, 95% CI 0.70-0.98), and family history of dementia (OR 2.07, 95% CI 1.18-3.63) were individual-level factors associated with prescription. Among 440 people considered having a need but received no prescription, 'declined by user/carer' was the main reason for not prescribing (70.7%). 'Carers/physicians having negative views on the effectiveness of non-pharmacological interventions', and 'carers unable to or not having the resources to collaborate' were the common reasons given.

**Conclusion:** A relatively low prescription rate of non-pharmacological interventions is related to both individual- and institution-level factors. Carer support and education, instrumental support, and prescription guidelines across specialities and sites are possible strategies to improve access to non-pharmacological interventions in dementia care.



# The use of Immersive Virtual Reality in Sensory Sessions on a Specialist Dementia Unit: Service evaluation of feasibility and acceptability

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## **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

### **Abstract**

**Aim:** Immersive Virtual Reality (iVR) technology is well established as a relaxation activity for older people but the technology is novel and unfamiliar to many staff on specialist dementia units and people with dementia alike. This service evaluation reviewed inclusion of iVR relaxation activities as part of routine Occupational Therapy sensory sessions on a specialist dementia unit.

**Method:** Twenty-five sessions were completed over 13 weeks with 14 participants. Nine participants chose to engage in multiple sessions. Feasibility was assessed through participant engagement and tolerability. Acceptability was assessed via structured review of user and staff feedback.

**Results:** Modal first session length was in the range '30 seconds-2 minutes'. This increased to 'over 2 minutes' on second sessions. There was a lack of significant adverse effects measured by direct questioning, neuropsychiatric assessment before vs. after sessions and adverse incident reporting. User and staff feedback noted positive experiences such as relaxation, openness to discussion, reminiscence, wider engagement and interest in future use.

**Conclusion:** This service evaluation suggests iVR can be successfully used as part of Occupational Therapy sensory sessions in a challenging clinical environment. Results support further evaluation in this user group and wider exploration of iVR across mental and physical health settings.



### Football vs. Alzheimer's

Mrs Elsa Ghio

Asociación Lucha contra el Mal de Alzheimer y Alteraciones semejantes de la República Argentina (A.L.M.A.), Ciudad Autonoma de Buenos Aires, Argentina

### **Topic**

Dementia research and innovation: Non-pharmacological interventions

### **Abstract**

This project was an initiative of the Asociación Lucha contra el Mal de Alzheimer y Alteraciones Semejantes (A.L.M.A) together with the magazine El Gráfico, based on the original project of the Fundació Salut i Envelliment of the Universidad Autónoma de Barcelona, the magazine Líbero and the advertising agency LOLA MullenLowe.

It is a special edition of the El Gráfico magazine with a selection of 10 articles on historical football events, intervened with cognitive stimulation and reminiscence exercises, aimed at people with Alzheimer's disease.

Under the slogan "Passion overcomes forgetfulness", A.L.M.A., together with El Gráfico magazine, launched this therapeutic tool for people with dementia. The publication was based on a study that showed that talking about football stimulates memory, attention and mood in people with dementia

The project was under the medical direction of Dr. Fernando Taragano, a leading mental health specialist. The aim of the magazine was to provide an evidence-based tool that assists cognitive stimulation through reminiscence, reinforces identity, sense of belonging and increases self-esteem through the passion generated by sport. Football. It can also be used as a resource to maintain active and healthy aging in the case of healthy older adults.

With a print run of 10,000 copies, this unique edition, published with the same aesthetics that characterized El Gráfico magazine in past decades, was distributed free of charge throughout the country in senior citizen centers, the National Secretariat of Children, Adolescents and Family and the Secretariat of Social Integration for the Elderly of the Government of the City of Buenos Aires.

#### More info:

www.futbolvsalzheimer.org.ar

Video presentation: https://youtu.be/qgjqAwWFH0Y

Magazine https://www.alma-alzheimer.org.ar/images/futbolvsalzheimer/elgrafico-fva-2022.pdf 0



# The 'DemChamp' study: Using illustration as a visual method to involve people affected by dementia in research

**Dr Monica Leverton**, Dr Tiffeny James, Ms Christina Newton, Dr Kritika Samsi King's College London, London, United Kingdom

## **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

### **Abstract**

**Aims:** The 'DemChamp' study aimed to refine and develop the role of Dementia Champions (DCs) in homecare as a potential solution to workforce challenges. Using illustration as a visual method sought to enable meaningful co-production with people affected by dementia and homecare staff; perspectives often underrepresented in research.

**Methods:** Drawing on earlier findings across health and social care, a co-production workshop using illustration explored the DC role in homecare. Workshop participants included people living with dementia, care partners, and homecare staff. An illustrator created visual scribes from discussions that were projected in real-time onto a large screen. A visual model of a DC in homecare was developed from the scribes and used as a visual elicitation tool to facilitate interviews with homecare staff and people affected by dementia to understand practice implications.

**Results:** The use of illustration in co-production was perceived positively. People living with dementia were enabled to participate as active members of the workshop, describing the illustration method as 'novel' and 'innovative'. Seeing the progression of the scribes in real-time allowed for ongoing member-checking, increasing validation. In-depth discussions with people affected by dementia and homecare staff were facilitated by the visual representation of a DC in homecare.

**Conclusion:** Illustration can encourage accessibility and inclusivity in research with people affected by dementia, and the homecare workforce. The use of illustration to aid co-production was perceived as an innovative method that enabled meaningful engagement. Findings from interviews using the visual model of a DC in homecare will be discussed further.



# An analysis of how intergenerational practices can contribute to South Asian social integration in the West Midlands, United Kingdom. (working title)

### Miss Zakiyyah Ahmed

University of Wolverhampton, West Midlands, United Kingdom

### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

## **Abstract**

This study will investigate social inclusion amongst South Asian older people aged 65+ in the West Midlands, United Kingdom.

### Secondary research

- To identify the key factors affecting older adults' social inclusion (this includes individuals with dementia)
- To evaluate the social inclusion initiatives for older South Asian people in the UK

#### **Primary research**

- To examine the views of South Asian older people in the West Midlands regarding their social inclusion
- To examine professionals' views on older South Asian social inclusion
- To evaluate if intergenerational practices can promote social inclusion of South Asians in the West Midlands
- To establish adults' (aged 18-64) views on participating in intergenerational activities with older individuals (aged 65+)

A mixed methods approach will be used: semi-structured interviews with older South Asian individuals in the West Midlands, United Kingdom, and a survey with individuals aged 18-64 and professionals. Additionally, an intergenerational workshop with South Asian adults (65+) and young people will be organised.

All the results from the literature review indicate that older South Asian individuals are experiencing significant social isolation in the UK due to insufficient and ongoing social inclusion practices. However, evidence suggests that they can benefit from intergenerational approaches. Thus, they reported an enhanced well-being, sense of belonging and confidence. Therefore, it is crucial to expand such intergenerational practices to improve South Asians' (65+) social inclusion.



# GEOspatial features, COgnition and DEpressive Symptoms in older users of municipal home care services, (GEO-CODE): A pragmatic clinical study.

**Dr Eliza Eleni- Zacharoula Georgiou**<sup>1</sup>, Miss Maria Brouma<sup>2</sup>, Dr Savvina Prapiadou<sup>1</sup>, Miss Kiriaki Premtou<sup>3</sup>, Prof Apostolos Vantarakis<sup>2</sup>, Prof Kostas Tsichlas<sup>4</sup>, Mr Vasileios Thomopoulos<sup>4</sup>, Prof Panagiotis Alexopoulos<sup>1,5,6</sup>

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### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

### **Abstract**

**Introduction:** Particularly pronounced in older adults living in underserved rural and semi-urban areas, depressive symptoms serve both as potential risk factors and early indicators of cognitive impairment. Our study, conducted in Western and Southern regions of Greece, explores the prevalence of depressive symptoms among older users of municipal home care services and investigates their intricate connection with cognitive function, considering demographics, clinical factors, and geographical data.

**Methods:** This study was conducted between 2020- 2022 in mainly low-resource areas within the 6th Health Region of Greece. We employed the Geriatric Depression Scale (GDS-15) for depression screening and the Clock Drawing Test (CDT) for cognitive evaluation. Sociodemographic, medical, and medication information was collected. Further neuropsychiatric assessment was recommended for individuals with depressive symptoms.

**Results:** 425 older municipal home care service users (mean age 80.6, 70% female, average education 3.9 years, mean comorbidities 3.7) across eleven counties were considered: In addition to 18 with previously diagnosed depression, 218 had GDS scores > 4. Thus, 55.5% of study participants had depressive symptoms. They scored lower on the CDT (mean 1.56, SD 1.059) compared to those without depression (mean 2.03, SD 1.015). Among 218 participants referred for neuropsychiatric assessment, data were obtained from 184 individuals. Only 69 (37.5%) visited physicians, while 40 (16.9%) consulted neurologists or psychiatrists. Seeking neuropsychiatric care correlated positively with higher income, economic output, prior neurological diagnoses, and inversely with age and population density.

**Conclusions:** Depressive symptoms, affecting over 55% of vulnerable older adults in rural and semiurban areas, are closely tied to cognitive decline. Unfortunately, the utilization of neuropsychiatric care remains low, influenced by socioeconomic disparities, medical history, age, and population density. Addressing these disparities is of paramount importance and future initiatives should prioritize improving access to mental health services and bolstering local healthcare systems' capacity.



# Dementia Friends Unite: Exploring co-creation experiences of a culturally inclusive dementia education initiative

**Ms Gabriela Elisa Caballero**<sup>1</sup>, Ms Eman Shatnawi<sup>1</sup>, Ms Ava Murali<sup>2</sup>, Prof Genevieve Steiner-Lim<sup>1</sup>, Dr Joyce Siette<sup>3</sup>, Prof Ann Dadich<sup>4</sup>, Prof Nicky Morrison<sup>5</sup>, Dr Diana Karamacoska<sup>1</sup>

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# **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

### **Abstract**

**Background:** Culturally and linguistically diverse (CALD) people living with dementia and their carers experience barriers to appropriate and accessible support compared to non-CALD people. Education for communities and workforces is needed to promote understanding about dementia, services, and inclusive practices. Co-creation encourages collaboration between service providers and service users to develop sustainable dementia education initiatives.

**Aim:** We evaluated the engagement of a diverse advocacy group in co-creating a multilingual dementia education initiative.

**Method:** Six hybrid workshops were facilitated with an advocacy group comprising 8 people with lived and caring experiences of dementia and 3 service provider representatives from English, Arabic, Vietnamese, Chinese, and Greek backgrounds. Researchers (n = 2) completed the project-specific public and patient engagement evaluation tool (PPEET) to probe preparedness, while advocacy group members (n = 6) completed the participant-specific PPEET to assess engagement. Data were descriptively analysed and open-ended questions underwent content analysis. Findings were narratively synthesised to provide a rich understanding of researcher-participant experiences.

**Results:** Researchers indicated high preparedness for collaboration, design, and process integrity, with moderate planning satisfaction and confidence. Participants indicated high agreeableness related to participation support and sharing of views, but moderate agreement on impact of engagement. Participants valued experiential diversity and recommended greater representation of under-served groups.

**Discussion:** Findings suggest concordance between researcher preparedness and participant engagement during the project's co-creation phase. The PPEET modules will be administered at two more time points as ongoing engagement can lead to more relevant and equitable outcomes. This project offers practical insights on co-creation efforts with diverse stakeholders.



# Understanding Dementia in Latin America: A Comprehensive Characterization

**Dr Lina Maria Zapata Restrepo**<sup>1,2,3</sup>, Dr Katherine Possin<sup>3</sup>, Dr Isabel Elaine Allen<sup>3</sup>, Dr Agustin Ibañez<sup>3,4,5</sup>, Dr Juan Rivas<sup>1,6,7</sup>, Dr Carlos Dorado<sup>1,8</sup>

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# **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

### **Abstract**

**Background:** The Latin American region is experiencing a growing aging population and an increasing prevalence of dementia. However, dementia patients in this region face challenges like underdiagnosis and a lack of comprehensive understanding. These problems are exacerbated by a shortage of culturally appropriate diagnostic tools and the diversity among Latinos, which affects how dementia manifests. Additionally, most genetic research in this field focuses on European populations, worsening healthcare disparities. Innovative technology for cognitive assessment and genetic analysis show promise for improving early and accurate dementia diagnosis in Latin America.

**Methods:** We conducted a comprehensive evaluation of a Colombian sample of people with dementia (n=43). Participants were previously diagnosed with FTD (N = 20), early-onset Alzheimer's disease (AD) (N = 23), as well as a control group (N = 40) using clinical diagnosis of probable AD or probable FTD behavioral variant using current diagnostic criteria for AD and FTD. The evaluation included a sociodemographic survey, an assessment of psychiatric and behavioral symptoms (the Neuropsychiatric Inventory; NPI), and a cognitive evaluation(TabCAT). We collected family history information and conducted genome sequencing to identify both known and novel genetic mutations associated.

**Results:** The majority of individuals were female (67%). The mean age was approximately 63 years. The mean education level was similar between the dementia group (12.4 years) and the control group (12.9 years). The majority of both AD (64%) and FTD (65%) cases fell within the lower socioeconomic status categories (1-3). Both FTD and AD patients exhibited neuropsychiatric symptoms, but the specific symptoms and their prevalence differed between the two groups.

**Conclusions:** These results offer valuable insights into the sociodemographic characteristics and neuropsychiatric symptoms related to dementia in a diverse and underrepresented population in research. Further research is required to delve deeper into these associations and determine potential contributing factors.





# Recruitment Strategies for Turkish Immigrants with Dementia and Their Family Caregivers in Dementia-related Studies: A Scoping Review

**Ms Esma Inam**<sup>1</sup>, Mrs Seda Güney<sup>2</sup>, Ms Kübra Altinok<sup>1</sup>, Mr Mike Rommerskirch-Manietta<sup>1</sup>, Prof Martina Roes<sup>1</sup>

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### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

### **Abstract**

**Aims:** The aim of this scoping review is to describe the (most effective) recruitment strategies for engaging Turkish immigrants affected by dementia and their caregiving relatives, and to identify the barriers to recruitment of the hard-to-reach group and maintaining participation.

**Methods:** We reviewed references from peer-reviewed journals describing recruitment strategies of Turkish immigrants with dementia and their family caregivers. The eligibility criteria for selecting articles are determined by the PCC framework (P = Population, C = Concept, C = Context). We conducted searches in English within databases MEDLINE, PsycINFO, CINAHL, and Scopus, as well as in German within the local University databases with no restriction of date and study type between July 3rd-12th, 2023. The reference lists of the selected articles were hand-searched, and relevant articles were added to the shortlist.

**Results:** Totally 445 articles were screened, and 16 of them were included in the review. Eight of the studies focus on caregiving relatives, while the other eight of them target individuals affected by dementia. The choice of recruitment strategies depended on the specific target group. People with dementia were recruited predominantly through settings like senior centers, clinics, or home care (n = 5), followed by referrals by physicians (n=4) and the involvement of bilingual staff (n=4). Caregivers were mainly recruited through health and community organizations (n = 7), settings (n = 5), social networks, and the involvement of bilingual staff (n = 3). While facilitators played a crucial role in engaging caregiving relatives, language and cultural barriers remained as the most important barriers.

**Conclusions:** The persistent presence of language and cultural barriers requires a culturally sensitive approach to increase the involvement of Turkish Immigrants in dementia-related research.



# P39-001

# Characteristics Of People With Memory Impairment At A Neurology Clinic In Vietnam

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<sup>1</sup>Military Hospital 175, H Chí Minh, Vietnam. <sup>2</sup>Military Hospital 175, Ho Chi Minh, Vietnam

## **Topic**

**Dementia research and innovation:** Younger onset, Mild Cognitive Impairment (MCI) and mild dementia

### **Abstract**

**Aims:** We conducted this study to describe some characteristics of people complaining of memory loss at the neurology clinic of Military Hospital 175 and determine which characteristics are associated with the MoCA score and diagnosis.

**Method:** We conducted a descriptive cross-sectional study using convenience sampling. From June 1 to September 1, 2023, people visiting the neurology clinic at Military Hospital 175 with complaints of memory loss were examined and diagnosed based on DSM-5 criteria. The data we collected included age, gender, education, duration of condition, comorbidities, and MoCA score. Participants who declined to participate in or were unable to complete the MoCA were excluded. The data were analyzed using STATA 14.0.

**Results:** 78 people reported memory loss; 58 of them were female and 21 were male. The median age was 60, with an interquartile range of [55; 64]. The duration of condition ranged from 1 to 10 years, with the median and the interquartile being 1 [1; 3]. The majority of the education level was middle and high school graduates (78.0%). There were 23.1% of people with hypertension, 9.0% with diabetes, 7.7% with dyslipidemia, 2.6% with Parkinson's disease, and 1.3% with stroke and epilepsy. MoCA scores were between 12 and 28, and the median and interquartile were 22 [18, 24]. The MoCA score had a statistically significant positive correlation with hypertension (p = 0.010) and dyslipidemia (p = 0.023). Further evaluation revealed that 73.1% had mild cognitive impairment (MCI), 19.2% had subjective cognitive impairment (SCI), and 7.7% had dementia. The diagnosis was statistically associated with hypertension (p = 0.002) and dyslipidemia (p = 0.030).

**Conclusion:** People with memory decline at Military Hospital 175 were mostly female, at a median age of 60, and diagnosed with MCI. Individuals who have hypertension or dyslipidemia should be screened for cognitive impairment using MoCA.



### P40-001

# **Enjoying Life with Dementia – Preparing and cooking meals**

#### **Mr William Michael Yeates**

Dementia Alliance International, Sydney, Australia. Dementia Australia, Sydney, Australia

## **Topic**

Dementia risk reduction: Dementia and nutrition

### **Abstract**

As a progressive neurological disease, the diagnosis of Alzheimer's Disease brings with it a multitude of challenges that impact on every aspect of your life. These encompass cognitive issues (memory loss, behavioural changes, and your ability to carry out daily tasks), as well as social, emotional, physical, psychological, and financial challenges. As a result, over time, there is a significant change in the quality of life that you can experience post diagnosis.

Having been diagnosed with Younger Onset Alzheimer's Disease in August 2019 at the age of 59, this presentation is about the change in quality of life that I experienced when I started to prepare and cook my own meals. To overcome the barriers that I encountered in order to achieve this goal, I created my own Reablement Plan that consists of five steps – Person-centred Assessment, SMART goal, Developing your Plan, Implementing your Plan and Evaluation. Of particular importance, is the way that I changed each recipe so that the person living with Alzheimer's Disease is working collaboratively with their partner/care worker to prepare and cook each meal.

In presenting my Reablement Plan I hope to encourage others who are also living with dementia, to explore ways that they can enjoy a better quality of life – one that you value and has meaning. I also hope that my presentation helps to change people's perception about this disease.



# P40-002

# Alzheimer and the risk of undernourishment

### Mrs Lorène Gilly

France Alzheimer et maladies apparentées, Paris, France

## **Topic**

Dementia risk reduction: Dementia and nutrition

### **Abstract**

People living with dementia are at high risk of undernourishment. Weight loss and eating disorders should therefore alert those around them, family members, caregivers or professionals, who should not consider these changes as normal, linked to ageing process or to the disease itself.

Undernourishment is a disease related to a lack of nutritional intake that weakens the elderly because of muscular loss, lower immunity and loss of autonomy. Cognitive impairments related to Alzheimer's disease often cause this pathologic condition.

To address this specific issue, France Alzheimer, which is a member of the French Collective for the Fight Against Malnutrition, supports its local branches in setting up targeted awareness-raising actions towards people living with dementia, their caregivers and the general public. These actions are:

Implementation of culinary workshops, some of which are organized with hotel schools, to also raise awareness amoung the future professionals of the sector;

Conferences led by dieticians and nutritionists to inform caregivers and health professionals, whether they work at home or in nursing homes;

Raising awareness among pharmacists, who are often in contact with caregivers and people with dementia, so that they can identify and advise on the importance of nutrition;

Signature of a convention with the Union Française des Soins Bucco Dentaires (the French Union for dental care), to inform, train and create specific tools for dental surgeons;

Implementation, in 2022, of a specific training program for cooks working in nursing homes in order to know the risk and to adapt their cookings to the needs of people living with dementia;

Creation of adapted recipes, filmed and broadcasted on social networks;

In 2023: a cookbook created with a neurologist, a cook and volunteers from France Alzheimer's local branches, intended for the general public, health professionals, people living with dementia and their caregivers.





### P40-003

# Could cerebral fructose metabolism be a driver of Alzheimer's disease?

### **Dr Helena Popovic**

University of Sydney, Sydney, Australia

### **Topic**

Dementia risk reduction: Dementia and nutrition

### **Abstract**

Fructose is a simple sugar (monosaccharide), which when bonded with glucose makes table sugar (the disaccharide, sucrose). When humans consume excessive amounts of fructose, it leads to mitochondrial oxidative stress, local inflammation and progressive reduction in cerebral energy (ATP) levels. The fall in intracellular ATP generates uric acid which leads to insulin resistance and reduced endothelial nitric oxide. All these factors lead to insufficient energy for neurons to remain functional and viable, eventually leading to the clinical picture of Alzheimer's.

In addition, when glucose is consumed in excess (by eating a diet high refined starches), the glucose can be converted to fructose. The enzyme required for the conversion of glucose to fructose is enhanced in the presence of salt, alcohol or dehydration, all of which are modifiable dietary factors.

This presentation is a meta-analysis of the mechanisms by which sugar could contribute to Alzheimer's and other dementias. This is of critical importance given the ubiquity of sugar in our current diet and the potential to prevent dementia on a massive scale through reducing intake. If people understand the brain-damaging effects of excessive sugar consumption (especially when combined with salt and alcohol), they will be more motivated to make dietary changes.

This knowledge will also provide incentives for governments to regulate the marketing of ultra processed foods and drinks that are high in sugar and to implement health warning labels.



### P41-001

# Alzheimer's disease is not destiny.

#### **Mrs Christine Tabuenca**

Fondation Médéric Alzheimer, Paris, France

## **Topic**

Dementia risk reduction: Public health campaigning

## **Abstract**

1 out of 2 French people has in his relatives a person with dementia. By 2050, dementia is expected to affect 2.2 million people, a real public health challenge to be adressed.

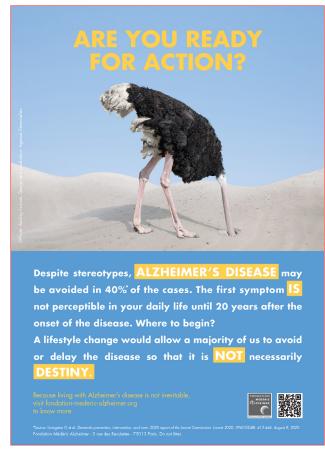
While research is progressing, it will not be able to meet all the needs and expectations of the 1.2 million people living with dementia today.

The most realistic hope lies in prevention: in fact, 40% of cases could be avoided [1]. According to a survey in the general french population lead by Fondation Médéric Alzheimer [2], French are familial with the disease and its symptoms and 75% declared themselves afraid of it. But the most striking finding of this survey highlights a high level of misinformation regarding Alzheimer's prevention. In fact, less than 1 French out of 10 knows that there are ways to prevent the disease or to slow the onset of symptoms.

Since Alzheimer's disease is too often perceived as an inevitable consequence of aging, the Foundation, faithful to its mission of general interest, has launched a 360° awareness campaign aimed at breaking down preconceived ideas. Alzheimer's disease must no longer be associated with a fatality. French people, especially those aged 45-60, are invited to take an active role in their own ageing by adopting more virtuous behaviours, because it is in this age group that the first symptoms of the disease appear and it is perhaps easier to change one's lifestyle.

The campaign is available in different formats: video clip, radio spot, posters, banners, dedicated website. Contrary to the classic codes of public health messages, the campaign delivers an educational message that is neither guilt-inducing nor moralistic. The Foundation has also launched a free fun challenge to raise

awareness « Together, let's challenge Alzheimer's disease » with the support of the Kiplin application.





# Social connections and risk of incident mild cognitive impairment, dementia, and mortality in 13 longitudinal cohort studies of ageing

Dr Suraj Samtani, Dr Gowsaly Mahalingam, Prof Henry Brodaty

Centre for Healthy Brain Ageing, Discipline of Psychiatry and Mental Health, School of Clinical Medicine, UNSW, Sydney, Australia

### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aim:** We examined the associations between social connection structure, function, and quality and the risk of our primary outcomes (mild cognitive impairment, dementia, and mortality).

**Method:** Individual participant-level data were obtained from 13 longitudinal studies of ageing from across the globe. We conducted survival analysis using Cox regression models and combined estimates from each study using two-stage meta-analysis. We examined three social constructs: connection structure (living situation, relationship status, interactions with friends/family, community group engagement), function (social support, having a confidante) and quality (relationship satisfaction, loneliness) in relation to the risks of three primary outcomes (mild cognitive impairment, dementia, and mortality). In our partially adjusted models, we included age, sex, and education and in fully adjusted models used these variables as well as diabetes, hypertension, smoking, cardiovascular risk, and depression.

**Results:** Social connection structure (being married/in a relationship, weekly community group engagement, weekly family/friend interactions) and quality (never lonely) were associated with lower risk of incident MCI. Social connection structure (monthly/weekly friend/family interactions) and function (having a confidante) were associated with lower risk of incident dementia. Social connection structure (living with others, yearly/monthly/weekly community group engagement) and function (having a confidante) were associated with lower risk of mortality.

**Conclusion:** Evidence from 13 longitudinal cohort studies of ageing indicates that social connections are important targets for reducing risk of incident MCI, incident dementia, and mortality. Our results provide actionable evidence that social connections are required for healthy ageing.



# Influencing Factors of Cognitive Function in High-Risk Groups of Dementia in One Area: Focused on Elderly Living Alone

Mrs Daeun Kim<sup>1</sup>, Dr Jeonglan Kim<sup>1</sup>, Mrs Yunhee Lee<sup>1</sup>, Dr Soyeon Jeon<sup>2</sup>

<sup>1</sup>sejong Dementia Center, Sejong City, Korea, Republic Of. <sup>2</sup>chungnam National University Hospital, Daejeon City, Korea, Republic Of

### **Topic**

Dementia risk reduction: Risk factors

### **Abstract**

**Background and objectives of the study:** This study conducted to identify the relationship between sociodemographic and physical health, mental health, living habit and environment factor that affect cognitive function of elderly living alone in one area.

**Methods:** This study were surveyed for 400 elderly people living alone in one area for a month in August 2021 and analyzed factors affecting cognitive function through multiple regression analysis.

**Result:** The demographic and cognitive function with difference were sex, age, education, economic activities, monthly living expense, leisure, visual, auditory. The physical health, mental health, living habit, environment factor and cognitive function with differences were balance, physical activity, frail, sarcopenia, area. The factors affecting cognitive function was education, economic activities, monthly living expense, instrumental activities of daily living, hope.

**Conclusion:** This study identified the factors affecting the cognitive function of the elderly living alone, and the most influential factor was IADL. This study is meaningful in developing the basis of a program to prevent and manage cognitive decline in the elderly living alone.



# Effects of APOE, depression, and anxiety on cognitive decline among adults at risk for Alzheimer's disease

Mrs Lea Hemphill<sup>1</sup>, Dr Jacob Jones<sup>2</sup>, Mr Cameron Ryczek<sup>2</sup>, Ms Rhiannon Rivas<sup>3</sup>

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### **Topic**

Dementia risk reduction: Risk factors

### **Abstract**

**Aims:** Alzheimer's disease (AD) is a widely recognized neurodegenerative disorder distinguished by degeneration of brain cells, a decline in memory, thinking, independence, and cognitive loss. Early diagnosis and interventions are very important. This study aims to examine the effects of depression/anxiety and APOE ε4 on cognitive decline to help improve the prediction of cognitive decline over time. It was hypothesized that the presence of depression/anxiety and APOE 4 will increase the risks for cognitive decline, and depression/anxiety and APOE ε4 will interactively affect cognitive decline.

**Methods:** Participants (N=947) obtained from the ADNI database were assessed for depression, anxiety, and cognition over three years. All participants were tested for APOE 4, assessed for depression/anxiety (NPI-Q), and completed a series of seven neuropsychological tests at baseline and every six-month follow-up. Multilevel- modeling was used to examine the longitudinal association between APOE  $\epsilon$ 4, depression/anxiety, and cognition.

**Results:** Our results indicated a significant three-way interaction between APOE  $\epsilon$ 4, occasion, and depression/anxiety predicting delayed recognition, global cognition, processing speed, word retrieval, and verbal fluency. Delayed recall was significant only for three-way interaction (APOE  $\epsilon$ 4 x occasion x depression).

**Conclusion(s):** Our findings supported that participants with APOE  $\epsilon$ 4 and depression/anxiety are at higher risk for cognitive decline. Findings further suggested that older adults may be more vulnerable to the neurotoxic effects of depression/anxiety, and better management of depression/anxiety could potentially reduce cognitive decline and dementia risk.



# The relationship between physical activity and non-modifiable risk factors for Alzheimer's disease and related biomarkers: A UK Biobank investigation

Miss Felicity Spencer, Dr Richard Elsworthy, Prof Leigh Breen, Dr Jon Bishop, Prof Sarah Aldred University of Birmingham, Birmingham, United Kingdom

### **Topic**

Dementia risk reduction: Risk factors

### **Abstract**

**Aims:** The likelihood of developing Alzheimer's disease (AD) is influenced by the non-modifiable risk factors, *APOE* genotype and sex. Physical activity can modify this risk, with increased physical activity reducing AD onset and progression. Changes in brain volume are evident in AD development and are influenced by these variables. This study aims to explore how physical activity, *APOE* genotype, and sex impact brain volume and risk of developing AD.

**Method:** Data from 69,154 UK Biobank participants (54.62% female; mean age (years):62.28, SD:7.84) were analysed. Outcomes included AD diagnosis, ventricular cerebrospinal fluid volume, and total brain volume. Physical activity was measured using objective (average acceleration via accelerometers) and subjective (IPAQ scores) methods. Regression models, adjusted for health and lifestyle covariates, were used for analysis.

**Results:** Lower levels of objectively measured physical activity and *APOE4* genotype were associated with AD diagnosis. Additionally, ventricular cerebrospinal fluid volume decreased as levels of objectively measured physical activity increased, with a sex interaction: men experienced a larger decrease in volume (29%) than women (19%) as exercise level increased. Subjectively measured physical activity predicted total brain volume alone; people with moderate activity levels had larger total brain volume than those with low activity levels.

**Conclusion:** The results emphasise the importance of physical activity for reduction of AD risk and maintenance of brain volume. They suggest that tailored physical activity interventions may be preventive for AD. Further research is needed to better understand the sex-related differences in ventricular cerebrospinal fluid volume and how this influences AD risk.



# Keep your brain healthy: development and evaluation of an e-learning tool on dementia risk reduction

Miss Stephanie van Asbroeck<sup>1</sup>, Miss Sophie Wimmers<sup>1</sup>, Mr Rob Groot Zwaaftink<sup>2</sup>, Mr Dinant Bekkenkamp<sup>2</sup>, Miss Vera Otten<sup>2</sup>, Dr Martin van Boxtel<sup>3</sup>, Dr Sebastian Köhler<sup>4</sup>, **Dr Kay Deckers**<sup>4</sup>

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### **Topic**

**Dementia risk reduction:** Risk factors

### **Abstract**

**Aims:** Many people are unaware of the potential for dementia risk reduction, but state they would appreciate more information on this topic. Raising awareness is important as a first step towards behavior change. The knowledge that a set of lifestyle behaviors is beneficial for your cognitive health may also provide additional motivation.

**Method:** An online, free e-learning on the topic of dementia risk reduction for the Dutch adult population will be developed (in co-creation with Alzheimer Netherlands). It will cover the following topics: physical activity, healthy diet and alcohol consumption, cognitive activity, mental wellbeing including social wellbeing and sleep, cardiovascular health, and lifestyle coach-guided advice on how to make sustainable lifestyle changes. The content of the e-learning will be delivered in stages, so that completion of the full course takes approximately seven weeks.

**Results:** The e-learning's effectiveness in terms of knowledge acquisition, evolution in motivation for health behavior and actual health behavior improvements will be assessed with validated questionnaires in a pre-post study. Participants (N=430) will complete an online survey before starting the course, immediately thereafter and again three months later. User experiences and engagement with the e-learning materials will also be evaluated.

**Conclusion:** Awareness of the potential for dementia risk reduction is currently lacking in the general population. An e-learning is a low-level means that can be used to increase knowledge and awareness, and could further easily be implemented as a stand-alone tool or as part of current or future dementia risk reduction initiatives.



# Predictors of progression from subjective cognitive decline to objective cognitive impairment: a systematic review and metaanalysis of longitudinal studies

**Miss Ran An**, Prof Qiaoqin Wan Peking University, Beijing, China

## **Topic**

Dementia risk reduction: Risk factors

### **Abstract**

**Aim:** Subjective cognitive decline (SCD) is one of the first symptoms of dementia. With increasing awareness of brain health, a growing number of individuals seek medical assistance for purely subjective cognitive function decline. However, only individuals with specific characteristics tend to experience clinical progression. This study aims to summarize the predictors of objective cognitive impairment in individuals with SCD and to identify those at higher risk of clinical progression.

**Method:** We systematically searched 11 electronic databases from inception to February 1, 2023, for longitudinal studies investigating factors associated with the clinical progression of SCD. Effect sizes were pooled using fixed-effects and random-effects models. Leveraging the results of the meta-analysis, we developed two risk prediction models for objective cognitive impairment.

**Results:** Forty-six cohort studies were included in the systematic review, of which 28 met the meta-analysis criteria. Fifteen predictors were identified, including 4 biomarkers (amyloid  $\beta$  deposition, lower Hulstaert Formula scores, apolipoprotein e4, and hippocampus atrophy), four epidemiological factors (older age at baseline, impaired instrumental activity of daily living, depression, and anxiety), and seven neuropsychological factors (participants in clinical settings, older age at onset, stable symptom, concerns, cognitive decline confirmed by informant, severe symptoms, and poor performance on Trail Making Test B). Based on the meta-analysis results, we developed two risk prediction models. Model1 incorporates epidemiological and neuropsychological factors, distinguishing individuals with low and medium risk. Model2 includes additional biomarkers to enhance predictive performance and identify individuals at high risk.

**Conclusions:** This study provides a comprehensive characterization of individuals undergoing clinical progression from SCD to mild cognitive impairment or dementia. The developed models support the prediction of progression risk in both memory clinic and community settings, aiding in the early identification of individuals at risk of disease conversion and facilitating the translation of evidence into clinical practice.



# Multidimensional Risk Predictors for IADLs among Persons with Cognitive Impairment in Northern Taiwan: A Longitudinal Study

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### **Topic**

Dementia risk reduction: Risk factors

## **Abstract**

**Objectives:** Instrumental activities of daily living (IADLs) are complex tasks and associated with quality of life. However, few studies identified multidimensional risk factors and change of IADL in persons with cognitive impairment (PWCIs) based on the International Classification of Functioning, Disability and Health (ICF).

**Methods:** Guided by ICF, we designed a one-year longitudinal study with two time points to identify risk factors of IADL reported by patients and family caregivers (pIADL vs. fIADL). Eighty-two dyads were recruited to collect personal, function/structure, and environmental data. Hierarchical regression models and GEE were applied.

**Results:** Significant predictors of pIADL included function/structure factors-patients' Geriatric Depression Scale-Short Form (GDS-S) (p < .01) and environmental factors-daily caregiving hours (DCHs) (p < .05). While significant predictors of fIADL of PWCIs included function/structure factors-family reported Prospective and Retrospective Memory Scale (fPRMQ) (p < 0.01), and environmental factors: depression among caregivers, measured by the Center for Epidemiologic Studies Depression scale-10 items (fCESD) (p < 0.05), and DCHs (p < 0.05), explaining 35% and 63% of variance, respectively. Longitudinally, function/structure factors, especially GDS-S (p < .01), fPRMQ (p < .01), significantly predicted the change of slope for pIADLs. As to the fIADL, function/structure factors, such as Neuropsychiatric Inventory (NPI) (p < .05) and fPRMQ (p < .01), significantly predicted its change of slope, while environmental factors such as fCESD (p < .05) and DCHs (p < .01) also significantly predicted its change of slope.

**Conclusions:** The ICF can be applied to PWCIs. We identify risk factors of PWCIs' IADL. The function/structure and environmental factors predict the IADL of PWCIs and the slops of change in IADL. Tailored interventions can focus on function/structure factors, such as neuropsychiatric symptoms and depression, prospective memory, and environmental factors such as FCG depression and caregiving intensity, to maintain daily function of PWCIs





# myAvos: a technical solution for managing lifestyle to improve cognitive wellbeing

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OptiChronix, Basel, Switzerland

### **Topic**

Dementia risk reduction: Risk factors

### **Abstract**

Dementia numbers are due to double over the next twenty years, so the race for a cure is on. However, research says that modification of certain lifestyle factors could potentially reduce the numbers of people with dementia by 40%. This begs the question 'why are we not addressing this?'; especially when studies show this is possible. MyAvos is a smartphone app that can assess lifestyle, identify strengths and weaknesses and coach, at a personal level, habits that can maximise successful cognitive ageing. This could be done in person, but the numbers of personnel needed would be huge and not sustainable and many people in the future will be living far from the nearest clinics, especially in China, which will have 50% of global Alzheimer's disease patients by 2050.

The management of these increasing numbers of people with dementia is huge, especially with the wish to find and help people as early as possible. Technology has to be the solution. People can determine their own baseline through simple interaction with their phone. When things are not right, they will have objective information to share with professionals and the interaction will be more fruitful. The app is also designed to be shared with family members, so that everybody can see what is happening, not just with the person with cognitive impairment, but also those looking after them as well.

At OptiChronix, we see people with early cognitive impairment and caregivers as people who require more help than is currently on offer. myAvos is a technological solution that particularly helps these two groups, but also offers a key opportunity to prevent some cases of dementia and get people to professionals early, in an informed and productive way. We want you to see this app in action during your time in Cracow.



# Trajectories of depressive symptoms in the middle and elderly population and effects on cognitive function: A longitudinal Cohort in China

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### **Topic**

Dementia risk reduction: Risk factors

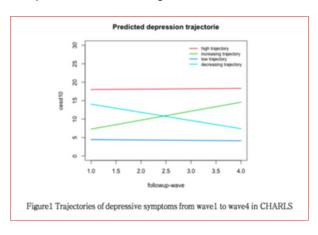
#### **Abstract**

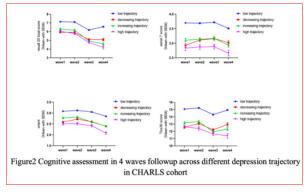
**Aims:** Late-life depression(LLD) which is a risk factor for dementia has a high heterogeneity in outcomes. This study aims to explore whether different depressive trajectories influence cognitive function

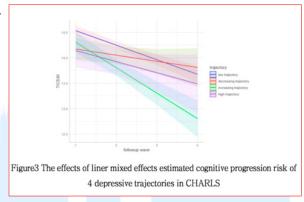
Method: Among the 8,454 over 55 years old participants in the CHARLS cohort, the Center for Epidemiological Studies Depression Scale(CESD), and the Telephone Interview for Cognitive Status 30 Modified(TICS30) were used to assess the depressive symptoms and cognitive function. TICS30 including word recall, serial 7, drawing picture, and orientation. Depression trajectories were classified based on the fluctuation of depression scales across four visits from 2011 to 2018 using latent class analysis. The impact of depression trajectories on cognitive function was examined using linear mixed models.

**Results:** In the CHARLS cohort, depression symptoms were divided into four trajectories: low trajectory (64%), decreasing trajectory (14%), increasing trajectory (15%), and high trajectory (7%). The increasing trajectory and high trajectory showed a significant cognitive decline during follow-up in overall cognition, word recall, calculation ability, and orientation (p= 0.001- 0.025). Even after adjusting for other covariates, the results remained consistent. However, the decreasing depression trajectory did not significantly affect cognitive function, especially in word recall (p=0.782).

**Conclusion:** This study suggests that multitimepoint depression evaluations in community cohorts are beneficial for determining depression symptom trajectories, offering early warning for cognitive decline.









# Raising awareness of modifiable risk factors for dementia: positive impact of a brief intervention

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Background:** There is growing interest in the potential to reduce dementia risk through lifestyle changes. Subjective cognitive decline (SCD) increases dementia risk, but little is known about individual's knowledge of dementia risk or their intention to make lifestyle changes.

**Objectives:** This study examined current knowledge of dementia risk and the impact of a single session intervention on the intention of individuals with SCD to make lifestyle changes.

**Method:** Twenty-eight men and 56 women aged 50-87 years completed an SCD measure and were randomly assigned to a brief educational intervention (N=42) – a video explaining modifiable risk factors and personal agency - or a control group (N=42) – a video containing general information about subjective cognitive decline. Primary outcomes were change in risk awareness and intention to make behavioural changes.

**Results:** At baseline, 64.29% of the sample believed that dementia risk could be reduced through lifestyle improvements. Risk awareness was increased by the modifiable risk factors intervention (p<.001). Individuals in the experimental condition with increased memory concern held significantly stronger intentions to adopt health guidance (p=.037).

**Conclusion:** The findings suggest that a brief educational intervention can increase awareness of dementia risk. In this sample of individuals with SCD, those who were more concerned about their memory at the start reported increased intention to change. This short intervention could be used to raise awareness about dementia risk in other populations and help individuals identify potential lifestyle changes they could make.



# The Profile of Depression, Anxiety, Sleep Disorder, and Their Impacts on Cognitive Function in Shanghai Community-Dwelling Older Adults

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### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** This study aimed to screen for anxiety, depression, sleep and cognitive disorders in community-dwelling older adults in Shanghai and to analyze the impact of anxiety, depression and sleep problems on cognitive function.

**Method:** This study comprehensively assessed depression, anxiety, sleep, and cognitive disorders in elderly Shanghai residents aged 60 and above across 17 districts. Our assessment included gathering sociodemographic data, utilizing electronic scales and cognitive assessment tools to evaluate depression, anxiety, sleep quality, and cognitive performance. We also provided primary diagnoses for these disorders. Ultimately, this study investigated the impact of depression, anxiety, and sleep-related issues on cognitive function.

**Results:** In this study involving 18,321 participants (mean age 71.9±6.2 years, 59% female, 8.2±4.7 years of education), we observed the following: 16,336(89.17%) had normal cognitive function, 1,770(9.66%) had mild cognitive impairment, and 215(1.17%) exhibited cognitive dysfunction. Regarding sleep, 15,842(86.47%) experienced no issues, while 2,479(13.53%) did. In terms of depression, 17,855(97.46%) were free of depression, 401(2.19%) had mild depression, and 65(0.35%) were clinically depressed. Lastly, 18,017(98.34%) reported no anxiety, 251(1.37%) had mild anxiety, and 53(0.29%) were anxious. Education and age significantly influenced cognitive function, with lower education and older age associated with more severe impairment (P<0.001). Sleep problems increased the incidence of mild cognitive impairment by 2.3 times (95% CI: 2.035-2.601, P<0.001) but did not exacerbate existing MCI. Depression also elevated the incidence of MCI by 2.5 times (95% CI: 1.335-4.546, P<0.005) with no impact on its severity. Anxiety and gender showed no significant influence on cognitive function (P>0.05).

**Conclusion:** Both sleep disorders and depressive disorders significantly elevated the occurrence of mild cognitive impairment in community-dwelling older adults aged 65 and above. In contrast, anxiety disorders did not exert a significant impact on the incidence of cognitive impairment.



# Awareness and attitudes towards dementia risk reduction in the Scottish population.

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** Dementia is a growing global concern, yet awareness about risk reduction remains limited. This study aimed to investigate factors influencing risk reduction awareness, attitudes towards understanding personal risk and motivation to lower risk in the Scottish population.

**Method:** A cross-sectional mixed-methods online survey (Qualtrics) administered in Scotland in May 2023. Multiple logistic regression was used to explore the associations between predictors (age, sex, income, education, rural residence, health literacy (HLS-EU-Q-16)) and (i) dementia risk reduction awareness (ii) motivation to change lifestyle for dementia risk reduction (MOCHAD-10) (iii) attitude towards personal risk. We also employed thematic analysis for insights from an open-ended question regarding risk prevention attitudes.

**Results:** Involving 941 adults (ages 18-86, median age 44, 47% male, 53% female), we found that those aged 18-24 (OR 0.52 95% CI 0.31-0.86) and 25-34 (OR 0.53 95% CI 0.34-0.81) were less likely to agree that dementia risk can be reduced, compared to age group 55+. Those with a higher education (UK level 6 or above) were more likely to agree (OR 2.32 95% CI 1.02-5.31), compared to participants without formal education. Factors motivating lifestyle changes included age between 35-44 (OR 1.61 95% CI 1.05-2.48), female sex (OR 1.65 95% CI 1.23-2.22), highest household income quintile (OR 1.90 95% CI 1.12-3.24), and urban residence (OR 1.56 95% CI 1.04-2.34), compared to rural. Participants aged 25-34 (OR 2.82 95% CI 1.52-5.43) and 35-44 (OR 2.56 95% CI 1.39-4.89) were more interested in understanding personal risk, compared to individuals aged 55+. Respondents highlighted the need for accessible information and professional support.

**Conclusion:** Our findings suggest that public health campaigns should raise awareness and promote dementia risk reduction strategies, particularly among younger individuals and those from less advantaged socio-economic backgrounds. Initiatives should prioritise providing accessible information and professional support to encourage lifestyle changes.



# Neighborhood-built environments and cognition in later life.

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Objectives:** Maintaining good cognition is crucial in later life. However, most existing research has focused on individual factors impacting cognition, and few studies have investigated the association between neighborhood-built environment and older adults' cognition. This study examined the association between neighborhood-built environments and cognition among community-dwelling older adults and identified variations in this association between different age groups in the older population.

**Methods:** Data were derived from a cross-sectional survey of 1873 people aged 65 years and above in Hong Kong. We merged individual data from the survey with neighborhood-built environment data based on community auditing and geographical information systems. After controlling for individual covariates, we used multivariable linear regression to examine the association between neighborhood-built environment and cognition.

**Results:** Residents aged 80 and younger in neighborhoods with a higher land-use mix and more public transport terminals exhibited better cognition. Only the number of community centers in a neighborhood was positively associated with cognition for people older than 80.

**Conclusion:** The built environment creates diverse impacts on different age groups among older adults. Our findings provide useful information for urban planners and policymakers for planning community facilities and built environments that consider the needs of different age groups within the older population.



# High Neutrophil-to-Lymphocyte Ratio in APOE ε4 Allele carriers increasing the Risk of DementiaJournal: Brain Behavior and Immunity

#### **Dr Jing Nie**

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### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** 1)To investigate the interaction between the status of APOE 4 and peripheral inflammation and its association with the risk of incidence of dementia. 2)To find the correlation between baseline neutrophillymphocyte ratio (NLR) stratification and cognitive function and AD pathology in a dementia-free sample prospectively during follow-up.

**Methods:** This cohort study used data from Shanghai Action of Dementia Prevention for the elderly projects (SHAPE) in China in 2020. Logistic regression analyses were conducted to explore the association of NLR with dementia in elderly with and without APOE  $\epsilon 4$  allele. In addition, an external sample from ADNI, underwent cognition and AD pathology assessments approximately 6 years after their NLR was assayed, to further confirm our results.

**Results:** We observed positive associations with risk for dementia with NLR in APOE  $\varepsilon$ 4 carriers in the multivariable logistic regression model (odds ratio for highest(Q4) vs lowest quartile(Q1),2.89, 95% CI ,1.23–6.79; P=0.015) in SHAPE after controlling for traditional demographic and lifestyle risk factors, but not in non-APOE  $\varepsilon$ 4 carriers. Furthermore, this corresponds to a rapid cognitive decline over a 6 years follow-up for APOE  $\varepsilon$ 4 carriersversus for non-APOE  $\varepsilon$ 4 persons in top quartile (Q4) of NLR from the ADNI(β=-1.694,p<0.001). In addition, the effects of NLR on cognitive function were mediated by total-tau and Aβ42/total-tau pathology (proportion: 23%~40%, p<0.05).

**Conclusions:** This study is the first to found association between peripheral inflammation and a higher risk of dementia in APOE  $\epsilon 4$  carriers in the Han Chinese population. Peripheral inflammation appeared to enhance the association between APOE  $\epsilon 4$  status and dementia, whereas total tau appears to be an important intermediate condition between the association of peripheral inflammation with AD in APOE  $\epsilon 4$  carriers. The study provides further insight for individuals targeting systemic inflammation, geared towards Alzheimer's risk reduction.



# Population-level interventions for dementia risk reduction

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<sup>1</sup>University of Cambridge, Cambridge, United Kingdom. <sup>2</sup>UCL, London, United Kingdom

### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** To summarise the best available interventional evidence for population-level dementia risk reduction.

**Methods:** (1) We reviewed published definitions of 'population-level interventions' and prevention frameworks to apply these approaches, then applied these to evidence on dementia risk reduction to create a definition of population-level dementia risk reduction interventions. (2) We conducted a rapid review to identify systematic reviews describing dementia primary prevention interventions, and measured the proportion of included interventions that met our definition. (3) We conducted a complex, multi-stage, evidence review to identify high-quality (e.g. Cochrane reviews, WHO literature), empirical evidence on population-level interventions for the modifiable risk factors identified by the 2020 Lancet Commission on dementia. We synthesised and graded evidence, and derived a dementia risk reduction population-level intervention framework for policymakers.

**Results:** (1) We define population-level dementia risk reduction as measures, applied to groups, that make societal conditions less conducive to the development of risk factors for dementia. (2) We identified 13 dementia primary prevention systematic reviews. Almost none (<2.5%) of the interventional evidence included in these reviews met our definition. (3) We make 26 evidence-based policy recommendations, constituting availability (n=8), legislative (n=8), fiscal (n=5), and marketing (n=5) interventions, with more than half supported by data from low- and middle- income countries.

**Conclusions:** Population-level interventions for dementia risk reduction have the greatest potential to reduce prevalence of, and inequalities in, dementia, but have been neglected to date. We present the best available evidence on population-level interventions for dementia's modifiable risk factors for policymakers to consider.



# Dementia risk reduction in primary care is feasible: a proof-ofconcept study using a smartphone app in the Netherlands

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### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** Currently, there is sufficient evidence that reducing the risk of dementia risk justify public health measures. However, implemented interventions are still scarce, especially on a large scale. In the Netherlands, evidence-based cardiovascular risk management is already implemented in primary care. Therefore, discussing dementia risk reduction alongside cardiovascular health in general practice seems to be a feasible, first step towards future large-scale implementation of dementia risk reduction strategies.

Method: A proof-of-concept study was conducted in ten general practices in The Netherlands. Participants aged 40-60 years (N=188), with room for improvement on ≥1 modifiable dementia risk/ protective factor, had a consultation with their general practitioner. Here, they learned about how to personally improve their risk profile. Practices were randomly allocated (1:1) to either provide the consultation only, or to additionally provide a brain health promotion smartphone app. Feasibility was evaluated using validated questionnaires assessing knowledge on dementia risk reduction, health behavior and experiences with the consultation and app. Surveys were administered before the consultation and three months thereafter. The primary outcome was the 'Llfestyle for BRAin health' score (LIBRA) which combines 12 modifiable dementia risk/protective factors.

**Results:** Overall, the consultation and smartphone app were positively perceived by most participants. The majority reported that the app supported them towards their lifestyle goals. The LIBRA score improved over time in both groups. Mediterranean diet adherence was improved at follow-up and even more so in the app group. Moreover, body mass index was significantly lower after the intervention but no between-group difference was observed. Knowledge of dementia risk reduction increased over the course of the study and increased more in the app group.

**Conclusion:** Discussing dementia risk reduction in the general practice and providing a brain health promotion smartphone app may constitute a feasible and effective, scalable approach towards dementia risk reduction.



# **Exploring Preferences and Challenges: User Testing of Cognitive Training Apps Among Older Adults**

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University of College London, London, United Kingdom

#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Background:** Dementia prevention is a pressing global public health concern. Research suggests cognitive training apps may stimulate cognitive function and offer older adults a potentially promising way to reduce their risk of dementia. However, the usage of such apps among older adults remains relatively low. Multiple factors contribute to this, including interface design and user gaming preferences. This study seeks to understand the experience, needs, preferences and challenges faced by older adults in using existing cognitive training apps.

**Method:** We recruited 60 cognitively healthy older adults (aged =>50) from various public settings around London. Participants played 2–6 cognitive games on a tablet device, from three cognitive training apps (Lumosity, Brain HQ, Neuronation). The selection of these apps was guided by user experience and scientific criteria, assessed through validated tools such as the App Behaviour Change Scale (ABACUS), the Mobile Application Rating Scale (MARS), and metrics from app stores, including download numbers and user ratings. A trained researcher observed participants' interactions with these games, noting preferences and any challenges encountered by the users. The user-testing sessions were audio recorded, transcribed and subsequently analysed using principles of thematic analysis.

**Results:** Our participants represented diverse ethnic and socioeconomic backgrounds, with various levels of literacy with technology. At the time of abstract submission, a formal qualitative analysis has not been completed. Nevertheless, Preliminary findings indicate preferences among older adults for games containing clear rules, word games that did not demand advanced language skills, and games with themes connected to their daily experiences. Considering app interfaces, participants favoured apps with larger text and audio feedback. I will present the method we employed for the selection of apps for user testing, and results of the usability testing In the conference. The findings will inform the development of a future cognitive training app for dementia prevention.



# Brain health knowledge and exposure to dementia risk factors in young adults across five continents

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aim:** Young adulthood is an important but neglected life stage for dementia prevention. Exposure to multiple lifestyle-related risk factors for Alzheimer's and related dementias (ADRD) begins during this life stage. However, young adults have largely been ignored in brain health research and extant evidence is limited to high-income countries. Our aim was to examine awareness and exposure to risk factors in a diverse young adult population.

**Method:** We developed an online brain health survey tailored to young adults in collaboration with Public and Patient Involvement advisors. The survey was translated from English into Spanish, Hindi, and Mandarin. Data were analysed using descriptive statistics.

**Results:** The current sample comprises 414 adults (55.7% female;  $28.4 \pm 5.3$  years) representing 36 countries (anticipated N = 5000). The proportion of participants identifying as LGBTQIA+ was 13.8% and those identifying as neurodiverse was 13.4%. Most participants (69.8%) reported being regular drinkers and nearly half said they smoke or vape. One third of participants reported using drugs, with cannabis being the most frequent. One third also reported having experienced at least one brain injury. Of these, 6.4% were due to intimate partner violence, with violent relationships lasting between 1.5–7.5 years. Over 90% of participants said they were regularly exposed to air pollution and 40.3% said they felt stressed daily or multiple times a week. In contrast, only half of participants had heard of the term 'brain health'. One in five participants said they get their health information from TikTok or other social media. When asked about genetic testing, 90.1% of participants said they would be interested in having their ADRD risk assessed.

**Conclusions:** Results provide a preliminary overview of young adults' awareness and exposure to ADRD risk factors, healthcare information access and attitudes towards genetic testing. This knowledge can inform life course prevention strategies.



# Knowledge of dementia and personhood in dementia among professional dementia care staff in Dubai, United Arab Emirates

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

**Introduction:** The United Arab Emirates, consistent with the global ageing trend, is predicted to see a rise in Emirates aged over 60 from 5.1% in 2017 to 19% in 2050. With an ageing population the numbers living with dementia and other conditions of aging is also predicted to rise. Currently there are only a handful of centres providing specialized care for dementia, and little is known about their models and training in dementia care, for example, the use of person-centred approaches.

**Objective:** To assess knowledge of dementia and the concept of personhood in dementia care in Dubai, United Arab Emirates.

**Method:** In this cross-sectional, within-groups study, 49 participants (F= 27; mean age 45 years [SD=8.79]) were recruited including physicians, registered nurses, assistant nurses, and physiotherapists. They completed the Dementia Knowledge Assessment Scale (DKAS; Annear et al., 2017) and the Personhood in Dementia questionnaire (PDQ; Hunter et al., 2013) along with demographic question items including age, sex, duration of employment, and position at the care facility via an online platform.

**Results:** Overall scores on the DKAS suggested that knowledge of dementia was above average whereas average scores on the PDQ indicated good understanding of personhood. However, further analysis of responses to specific items on both measures identified high levels of endorsement of incorrect items and areas of major inconsistencies and difference between respondents.

**Conclusions:** The findings indicate gaps in knowledge among dementia care staff in Dubai in the United Arab Emirates. The results can be used to inform development of person-centred training to enhance dementia care in Dubai and increase capacity to address the growing numbers of people living with dementia.



# Off-road cycle lanes can reduce the sex and gender differences in risk of dementia and are cost-saving

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### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims/Background:** Women have almost twofold increased risk of developing Alzheimer's disease compared to men. Physical activity (PA) is significantly associated with reduced risk of cognitive decline and dementia. There are gender differences in PA participation, and PA frequency declines with age, particularly in women, which might widen the gender difference in dementia incidence. Safety is one of the main factors strongly influencing the gender gap in PA. Off-road cycle lanes improve safety and enhance rider's confidence, leading to increased utilisation among women proportionately more than men.

**Method:** We adapted a published Markov model targeting middle-aged people in England to quantify the impact of increasing women's participation in PA and its effect on dementia incidence, relative to men, and associated health and social care costs. We examined various scenarios of increased PA facilitated by off-road cycle lanes, drawing from effectiveness estimates from the literature. We compared the costs of investing in off-road cycle lanes with the savings from reduced dementia incidence, noting the quality of life benefits too.

**Results:** Off-road cycle lanes increase PA in women more than in men, and thus help reduce the sex/ gender gap in dementia (incidence and years with dementia) and increase life-expectancy. However, the higher life-expectancy due to greater PA levels increases incidence of other diseases and their related costs. We examined whether the increased PA levels due to cycle lanes utilisation leads to lower overall costs for health and social care (i.e., whether there are net overall savings).

**Conclusion:** Physical Activity brings multiple health benefits and can be a protective factor for dementia incidence and cognitive decline. Off-road cycle lanes increase safety, reducing the sex/gender gap in PA, and thus the higher incidence of dementia among women, with potential savings in health and social care costs.



# A public health approach to dementia prevention in Italy: a critical reading and analysis of 21 regional prevention plans

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### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** According to the Lancet Commission 2020 report, 40% of dementia cases are attributable to 12 modifiable risk factors and could therefore be prevented through targeted actions at different stages of life. Our study aims to identify interventions for the prevention of dementia in the Regional Prevention Plans (PRPs) 2020-2025 in Italy.

**Method:** A critical reading of 21 PRPs was conducted to identify and analyze actions aimed at preventing the onset and progression of dementia, identified as dementia-specific actions by the National Prevention Plan. These were first classified according to the type of risk factor targeted and the age concerned and were also categorized according to the target population. Then, using keywords, all actions in the PRPs that could be identified as interventions aimed at reducing the risk from the 12 risk factors for dementia, but not recognized as dementia-specific actions, were identified.

**Results:** Dementia-specific actions included interventions on physical inactivity (20 PRPs), smoking (9 PRPs), alcohol consumption (8 PRPs), obesity (6 PRPs), social isolation (5 PRPs), diabetes and hypertension (4 PRPs), air pollution (2 PRPs), depression and head injury (1 PRP). No PRP considered hearing loss and low education as intervention areas. The targets of these actions were the general population (n=98), policymakers (n=64), health professionals (n=62), other (n=83). Using the keyword search, we found that all regions implemented preventive actions for physical inactivity and smoking and numerous actions were planned to prevent obesity, hypertension, and diabetes; only two PRPs implemented interventions to prevent hearing loss. None of these, however, are planned as preventive strategies for dementia.

**Conclusions:** An unconscious phenomenon of dementia prevention is taking place in our country. It is crucial to integrate the dementia preventive approach with other noncommunicable diseases and to invest in all risk factors.



Co-supplementation of niacin and iron(III) citrate from age 50 to 70 years is forecast to delay population-onset of Alzheimer's dementia profoundly beyond a five-year goal otherwise demanding consistent engagement in one-hour-daily of moderate-intensity leisure-time physical activity: simulated double-blind, randomized, placebocontrolled interventional trials using real-world data with prolonged follow-up

#### **Dr Dmitry Kats**

HOM3OSTASIS, Research Triangle Park, USA

#### **Topic**

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** A hypothetical treatment that impedes Alzheimer's dementia (AD) onset by five years becoming available in 2025 will save millions of lives and trillions in costs. Degenerative consequences post-COVID-19 highlight an urgent need to counter a pending global crisis. This study aimed to ascertain the causal effects of two lifestyle interventions from age 50 to 70 years on the age of incident AD: (1) leisure-time physical activity (*LTPA*) or (2) niacin with iron(III) citrate supplement (*Niaciron*)

Method: Using well-characterized, population-based, prospective cohort data from the Atherosclerosis Risk in Communities (ARIC) Study of African-American and Caucasian, middle-aged, community-dwelling women and men at baseline (1987-1989) followed into older adulthood, Monte Carlo Markov Chain-iterated Bayesian joint modeling was applied to accommodate informative attrition,

(LTPA) or co-supplementation of niacin and iron(III) citrate ( Niaciron ) on the age of incident Alzheimer's in ARIC Study participants (N = 14,618) None Meeting PA guidelines Exceeding guidelines Tripling Guidelines weekly energy expended via LTPA: every extra 300 MET-min / 1 h expended 1,500 300 750 1.200 2.100 1.800 weekly leisure-time of 5-MET activity: each extra 1 h (e.g., walking, elliptical, golf 2.5 h weekly energy expended via Niaciron 8,031 MET-min (equivalent to alternatively, a weekly average of ~27 h of 5-MET LTPA) assuming no engagement in LTPA (i.e., 0 MET-min via LTPA) from age 50 to 70 years 87.0 88.0 88.3 88.8 simulated\*\* age (years) of Alzheimer's

permitting unbiased estimation on the age of AD incidence (per clinically-validated diagnoses) according to metabolic equivalent of task (MET)-minutes/week expended from age 50 to 70 years by *LTPA* – converted from repeated standardized assessment of exercise/sport activity collected prospectively in ARIC – or by *Niaciron* – computed utilizing measures extracted from literature review and preliminary investigations. Double-blind, randomized, placebo-controlled interventional trials were simulated to determine the potentially causative impact of energy expenditure through either *LTPA* or *Niaciron* over the fifties and sixties on AD development in older adulthood.

**Results:** Among 14,618 ARIC Study baseline participants (26% African-American; 55% women; mean age=54), 2,540 (17%) were diagnosed with AD thereafter a median follow-up of 23 years. Postponing AD by five years – from age 86.3 in a sedentary population to 91.3 years – requires expending 2,100 MET-minutes/week from age 50 to 70 years (Table 1), achieved via 5-MET LTPA for seven hours/week or *Niaciron*, which provides 8,031 MET-minutes/week (~27 hours/week of moderate-intensity LTPA).

**Conclusion:** Aging adults adopting *Niaciron* defers onsetting AD beyond five years without requirement for LTPA.



# Untangling the mechanisms of cognitive reserve

#### **Dr Helena Popovic**

University of Sydney, Sydney, Australia

### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

Why are some people's brains riddled with amyloid plaques yet they seem to remain cognitively intact? Thirty years ago, Columbia University neuropsychologist Yaakov Stern found that people with a higher education or more intellectually challenging occupation were less likely to develop Alzheimer's. He postulated that mental stimulation might impart a buffer against the onset of clinical symptoms and coined the term 'cognitive reserve'. At first ridiculed by his colleagues, the concept of cognitive reserve is now recognised as a critical piece of the dementia prevention puzzle.

This presentation reviews our current understanding of the many and varied factors that influence cognitive reserve, its neural underpinnings, and how to translate these findings into practical public health recommendations and risk reduction strategies.

It has recently become evident that Alzheimer's disease is linked to the degradation of dendritic spines leading to a loss of synapses. Conversely, preservation of synapses strongly correlates to resilience to dementia. How might we preserve our synapses? Researchers led by Jeremy Herskowitz from the University of Alabama at Birmingham have identified several proteins that regulate dendritic spine length and density, and act as mediators of cognitive reserve. These include neuritin (NRN1) and Twinfilin-2. When we engage in activities that stimulate cognitive processes, we increase levels of NRN1, which helps to preserve existing synapses and create new ones.

Another under-recognised factor linked to cognitive reserve is strength training. The better a person's hand-grip strength in later life, the better a person's cognition. Yet most people are completely unaware of the importance of maintaining muscle mass as they age.

Rather than focusing disproportionate time and resources on eliminating pathology — which continues to yield disappointing or minimally effective results — we need to give more attention to educating the public about life-long brain-boosting habits and activities that keep our synapses firing.



# Laughter Yoga for the Health of Caregivers and People Living with Alzheimer's Disease\*

Mrs Sylvie Annette Dagenais-Douville

Laughter Institute, Longueuil, Canada. Laughter Yoga Internaitonal University, Mumbai, India

### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

While in a 6-week placement in gerontology training with War Veterans, I became fascinated with the work of a music therapist and witnessed the power music had on people living with Alzheimer's Disease (AD) who would become receptive and open up to the music. Years later I became a Laughter Yoga (LY) Teacher. This practice is a fun, light and fairly easy way to engage the para-sympathetic system and bring calm to the nervous system and I decided to apply LY to people living with AD and their caregivers. The response obtained during LY sessions was and still is very powerful and rewarding. Within minutes of being in a circle initiating repetitive exercises of smiling, simulated laughter (no humor), guided breathing exercises and music, I can see JOY and playfulness surfacing and the release of stress and anxiety is palpable! Caregivers also observe a lasting relaxed state in many AD participants. After 15 years of successfully working with this clientele I wonder if perhaps our Laughter is registered at the same brain "level" as music, therefore enabling us to recall sounds, words or emotions associated with pleasant feelings. Many things need to be elucidated regarding the mechanisms underlying LY effects, but my experience shows that our LY sessions are a success. When delivered properly, regular LY workshops could be a CAM (complementary and alternative medicine) for people with AD and their caregivers and, further, LY contributes to developing a beautiful and playful complicity among participants.



# **Education and Training for Informal Carers over 6 Years in A Day Care Center**

Ms Ying Hui Wu<sup>1</sup>, Ms Chia Yu Chiu<sup>2</sup>, Ms Hsiu Ling Lin<sup>2</sup>

<sup>1</sup>1. Twin-cheng Care & Create Studio, Taipei, Taiwan. <sup>2</sup>Sisters of Providence, New Taipei City, Taiwan

### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** Sisters of Providence had registered in Taiwan in 1956. It had started community care services in 2001 in New Taipei County. A dementia and disability mixed type day care center was set up in 2010.

**Cases and Family Support Group:** Up to August 2023, 56 attendants in the Center, among them 37 are the people with dementia.

The support group is open to family carers, volunteers in the day care and caregivers in the community. The nearby Fu Jen Catholic University Hospital sent 1 or 2 PGY (post-graduate year training) to observe group on-going and gave feedbacks at the end of the session from 2023.

**Education and Support:** The family support group has been carried on from 2017-2023, hosted bimonthly, six times a year. There are 8 to 12 participants each time, 2 hours for each session. The first hour will be mainly on the latest caregiving challenges and gains. The second hour will process beneficial topics for their informational, physical, mental and spiritual issues. Special topics are arranged to invite professionals sharing nutrition, gardening, arts, stress and emotion management etc.

**Conclusion:** We will introduce focuses, philosophy and approaches with flexible and practical methods to educate family carers promoting knowledge and quality of life. Moreover, to invite carers come back to the group after people with dementia had passed away. Those caregivers can share experience and concern others. It will be extension of altruism and inspiration.



# A Qualitative Exploration of the Provision of Person-Centred Care in Spousal Relationships

Miss Chiara Carparelli, Dr Gerard Riley

University of Birmingham, Birmingham, United Kingdom

#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Objectives:** This study aimed to investigate the differences in the quality of care provided by spousal carers when supporting their partners with activities of daily life, as well as the reasons for these variations.

**Methods:** 30 spousal carers were recruited and participated in interviews examining the differences across carers in how person-centred their approach to care was when describing how they provided support to their partner on everyday tasks. The VIPS framework was used as a framework for this evaluation. Participants were also questioned about the factors influencing their caregiving approach.

**Results:** The findings of this study demonstrate that the ideas of PCC can be applied to family settings, with the participants showing variations in the person-centredness of the care they provided. However, it was apparent however that many participants were unfamiliar with the principles of PCC and how they could be applied to everyday tasks. Participants reported a lack of information and guidance relevant to their caring role.

**Conclusion:** While this study suggests that PCC can be applied to family contexts, it highlights the need to address caregivers' knowledge gaps regarding PCC and to provide formal guidance on its implementations when providing support with daily tasks.



# Relationship Continuity and Person-Centred Care in Spousal Relationships: a mixed method study

Miss Chiara Carparelli, Dr Gerard Riley

University of Birmingham, Birmingham, United Kingdom

#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Objective:** This mixed-method study aimed to investigate the relationship between variations in relationship continuity and the extent to which spouses provide PCC.

**Method:** 30 spousal carers were recruited and interviewed about how they provide support to their partner living with dementia in everyday tasks. Each passage describing support for a particular everyday task was evaluated according to whether it suggested that the care provided was more or less personcentred. Participants also completed the Birmingham Relationship Continuity Measure (Riley et al., 2013) which assessed their experiences of relationship continuity. Correlation analyses were carried out between these measures.

**Results:** A significant correlation was found between higher scores on the relationship continuity measure and a greater number of passages suggesting more PCC. Although not statistically significant, a small correlation was found between lower scores on the relationship continuity measures and a greater number of passages suggesting less person-centred care.

**Conclusion:** This study suggests that promoting greater relationship continuity in couples could facilitate the provision of more person-centred care.



# Feasibility and Acceptability of a 'Dementia Awareness for Caregivers' (DAC) Course in Brazil, India and the UK

**Prof Aimee Spector**<sup>1</sup>, Ms Emily Fisher<sup>1</sup>, Dr Raquel Santos de Carvalho<sup>2</sup>, Dr Nirupama Natarajan<sup>3</sup>, Dr Esther Hui<sup>1</sup>, Dr Sridhar Vaitheswaran<sup>4</sup>, Ms Monisha Laksminarayanan<sup>4</sup>, Dr Paula Schimidt Brum<sup>5</sup>, Prof Cleusa Ferri<sup>5</sup>, Dr Elodie Betrand<sup>6</sup>, Dr Daniel Mograbi<sup>2</sup>, Dr Isabelle Evans<sup>1</sup>, Dr Ria Patel<sup>1</sup>, Dr Charlotte Stoner<sup>7</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** / aims: The paucity of brief, post-diagnostic interventions to support family careregivers led to the development of a 4-hour Dementia Awareness for Caregivers (DAC) course by a global team (Stoner et al, 2021). This research programme aimed to evaluate the feasibility, acceptability and impact of the DAC in Brazil, India and the UK.

**Methods:** Caregivers were randomized to receive the DAC or 'treatment-as-usual (n =36 Brazil, n=34 India, n=51 UK). The DAC, delivered online; included 'What is dementia?', 'Positive engagement' and 'Caregiving', the generic template modified for local populations. Standardised outcomes were measured at baseline and follow-up, alongside recruitment, retention, attendance, and adherence. Semi-structured interviews explored acceptability, impact, and changes in behavior and attitudes.

**Results:** The UK study found high retention and attendance, and low attrition. Analysis indicated positive trends in attitude, burden, competence and positive aspects of caregiving. Qualitative analysis generated four over-arching themes including observed impact and use of new skills. Brazilian and Indian data were combined for analysis (n = 70), again with high attendance, retention and low attrition. Significant improvements were observed in attitudes to dementia (p < .001) and competence (p = .040). Qualitative findings included recommended changes to the intervention and behaviour changes observed.

**Conclusions:** Offering a standardized yet flexible methodology, the DAC appears feasible and acceptable to deliver to groups of around 15 caregivers in diverse parts of the world. It now needs to be evaluated as a powered RCT. Brief interventions post-diagnosis may be a cost-effective way of educating and supporting caregivers, reducing the risk of problems developing later on.

Reference: Stoner, C. R., Lakshminarayanan, M., Mograbi, D. C., Vaitheswaran, S., Bertrand, E., Schimidt Brum, P., ... & Spector, A. (2021). Development and acceptability of a brief, evidence-based Dementia Awareness for Caregivers (DAC) course in low-and middle-income countries (LMICs). Dementia and Geriatric Cognitive Disorders.:



# iSupport - Further cultural and media adaptation of Australian iSupport for Dementia

**Prof Tuan Anh Nguyen**<sup>1,2,3</sup>, Ms Danielle McCalmont<sup>1</sup>, Dr Ron Sinclair<sup>4,5</sup>, Ms Adrienne Carmel Copley<sup>6</sup>, Prof Lily Xiao<sup>7</sup>, Prof Bianca Brijnath<sup>1</sup>, Prof Sunil Bhar<sup>2</sup>, Prof Penelope Schofield<sup>2,8</sup>, Prof Nilmini Wickramasinghe<sup>9,2</sup>, Dr Leanne Jack<sup>10</sup>, Dr Sarah Cullum<sup>11</sup>, Ms Tara Sani<sup>11</sup>, Prof Yuda Turana<sup>12</sup>, Dr Kham Tran<sup>1,3</sup>, Dr Thu Ha Dang<sup>1,2</sup>, Dr Andre Andrade<sup>3</sup>, Prof Adrian Esterman<sup>5,7,13</sup>, Prof Susan Kurrle<sup>14</sup>, Prof Maria Crotty<sup>7</sup>, Prof Ladson Hinton<sup>15</sup>, Prof Thang Pham<sup>16,17</sup>, Prof Henry Brodaty<sup>18</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Introduction:** iSupport for Dementia, an online education program for informal carers developed by the World Health Organisation (WHO), has been adapted into the Australian iSupport program. Carer feedback, however, showed that adapted iSupport interventions would be more accessible if presented in multi-media platforms which can be quickly searched to provide relevant advice in real-time. Our study aimed to fill this gap by furthering cultural and media adaptation of the Australian iSupport for Dementia program to translate its content into a series of animations, to be uploaded onto a Virtual Assistant platform.

**Methods:** The animations were co-designed with a culturally and linguistically diverse (CALD) committee of people who have lived experience caring for people living with dementia and healthcare professionals. A reiterative feedback approach was taken to ensure quality. Cultural norms and linguistics were closely considered and characters were developed to represent the diversity of the Australian population.

**Results:** Thematic analysis of feedback from the committee revealed further cultural adaptations needed to be made when adapting the Australian iSupport manual to animations. Themes that emerged included (1) the required shift from directive to a carer-centred approach; (2) carer preference for a supportive tone; (3) framing challenges positively; (4) the need to present realistic scenarios; and (5) cultural diversity.

**Conclusion:** Seeking several rounds of feedback from selecting and editing scenarios, to developing the script, storyboard and animation, allowed for optimised production but limited efficiency. Engagement with CALD communities, as members of the advisory committee, ensured appropriate representation.



# Effect of guidelines-based courses on second-year medical students' knowledge and reported practice towards cognitive impairments among the elderly

#### **Prof Junyu Zhao**

Fujian Medical University, Fuzhou, China

### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Background:** Cognitive function impairment remain a significant public health issue globally and may have adverse effects on activities of daily living and communication with others. This study aimed to assess effect of guideline-based course on second-year medical students' knowledge and reported practice towards mild cognitive impairment among the elderly.

**Method:** A Pre- and post-test research design was utilized in this study to assess second year medical students' knowledge and reported practice towards cognitive impairments among the elderly. 108 second-year medical students were participated and conducted in four phases: Pre-intervention assessment, guidelines-based cognitive rehabilitation course development, guidelines courses implementation, and post-test after two months. The pre- and post-tests were conducted online and included three parts to collect the required data about students' socio-demographic data, students' knowledge about the cognitive impairment senses and changes in these aspects among the elderly, and the students' reported practice for coping with changes in these senses among elderly. The chi-square and ANOVA test were used to compare means the score, and, pearson correlation coefficient was used for detecting the relations between continuous variables of the study.

**Results:** There are statistically significant differences between the studied subjects means score knowledge and reported practice about the cognitive impairment senses among elderly people in the preand the post-tests (P = 0.001). At pre-test the total score mean of students' knowledge,reported practice were all obviously improved compared with post-test. There is a postive relationship between students' knowledge and their reported practice at both pre-test and post-test.

**Conclusion:** Our study support the benefits that raising students' awareness through providing lectures, and workshops on cognitive impairment among elderly and how to deal with them, and train students on how to communicate with cognitive impairment among the elderly.



# Experiential knowledge of carers and its potential for peer support in Hungary

Dr Csaba Kucsera<sup>1</sup>, Ms Anna Holpert<sup>2</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

**Aims:** The analysis explores 1) the diverse journeys that carers take from laypeople to experts by experience; 2) carers' reflection on this learning curve that also affects their carer identity; and 3) how carers reflect on their experiential knowledge and evaluate its usability in advocacy and peer support.

**Method:** Qualitative research, thematic analysis of 29 in-depth interviews with carers and (allied) social care professionals.

**Results:** In the Hungarian context of a not very supportive formal care system, and with generally very little or no prior knowledge of dementia, the carers participating in the research made great efforts to improve their dementia-related knowledge and caring skills. It has helped them become more assertive, better stand up for themselves, be more confident in their abilities, and cope better with the complex caregiving challenges.

However, it has not been a smooth and trouble-free journey. They were interspersed with successes and failures, but they have been equipped with experiential knowledge that has enabled them to be critical of the formal care system and to consider helping their peers. Their reflection covered the validity and limitations of their knowledge and the usefulness of sharing it with their peers.

**Conclusion(s):** Peer support based on experiential knowledge has great potential in supporting carers' coping, especially in informational and emotional support and practical caregiving tips. Albeit there are a number of issues (e.g. the 'validity' of certain knowledge elements, the relationship between professional and experiential knowledge) that need further investigation, there is a clear need to strengthen peer support, as well as the ability to translate this expertise into service evaluation and -modernisation. As a general context, the research also raised issues of social solidarity and expectations related to the role of the state welfare system.



# Personalised support for informal caregivers of people with dementia (DemiCare)

**Dr Raluca Sfetcu**<sup>1</sup>, Prof Catalina Tudose<sup>1</sup>, Dr Tiberiu Ionescu<sup>1</sup>, Ms Julia Himmelsbach<sup>2</sup>, Mr Markus Garschall<sup>2</sup>, Ms Diotima Bertel<sup>2</sup>, Dr Giovanni Lamura<sup>3</sup>, Ms Francesca Gris<sup>3</sup>

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

Dementia is a slowly progressing disease with a wide range of symptoms. Hence, the needed strategies to interact with people with dementia vary as well as the pre-existing knowledge of family members and informal caregivers. While too much information at a time, e.g. provided via digital solutions, could overwhelm the caregivers and may cause worries, too little information may lose the interest in increasing personal knowledge. This holds not only for general information about care strategies for PwDs, but even more for different stages of the disease and comorbidities. DemiCare aims to provide personalized support for informal caregivers interacting with PwDs which is based on the social background (e.g. gender, locality and distance to the PwDs), pre-existing knowledge and general abilities of the caregiver and the relationship of the PwD and the carer, their social ecosystem, as well on the health status of the person with dementia. In DemiCare we will use Al-based technologies for personalized and diversity sensitive information extraction from specialist literature and present this information in an easy and understandable way. Additionally, caregivers are supported in terms of their well-being, e.g. by interventions for stress reduction. The integrated health monitoring of the PwD helps to increase the safety for the person but also supports the caregiver psychologically by having current information about the well-being of the person with dementia. In this poster we will present interim results from a four-month RCT conducted to measure the impact of the DemiCare app use on the well-being, health (including mental health) and burden of care of the informal carers of people with dementia conducted in Austria, Italy, Netherlands and Romania.



# A Case Study on Challenges to Care among Care Partners of People living with dementia

Dr Subhadra K T, Ms Sruthy K B

Kerala University of Health Sciences, Thrissur, India

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Introduction:** Dementia is one of the devastating disorders of the aged population. Just like the rest of the world, India is experiencing population aging and this demographic transition will have a significant impact on old age related conditions like Dementia. Dementia is a condition that has a huge physical, psychological, social, and economic impact on care partners and their families. In fact, care partner is termed "hidden patient" and they experience more significant challenges in providing care to persons living with dementia.

Case Description: Mrs. X has had severe dementia for 5 years now. She has been with her daughter who is her care partner since she was diagnosed with Dementia. This case is on the challenges and difficulties faced by the primary caregiver who somehow holds herself to look after her sick mother but is unable to fulfill many... When the investigator first saw Mrs. X, she was sitting in a damaged plastic chair with her hands and leg tightly tied and was having mucous throughout her face because her daughter was in the toilet.

**Conclusion:** Caregiving is itself a challenging situation in the case of persons living with dementia. Though Governments and NGOs help; is it really reaching the people who are in desperate need of it? A care partner was found to be suicidal because she could not bear the expense of looking after her mother.



# WHATSAPP GROUPS AS A COMMUNICATION TOOL FOR INFORMAL CARERS' SUPPORT

Dr Lorena Andrea Etcheverry Domeño<sup>1</sup>, **Mr Diego Aguilar**<sup>2</sup>, Prof Paula Andrea Millan<sup>3</sup>, Mrs Ivo Alen Espel<sup>3</sup>

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Introduction:** The person who cares for a family member diagnosed with dementia plays an important role in filling gaps in care in our health services. The impact of caring for a person with dementia is a significant threat to health. It includes emotional, physical, social, and financial burdens. Several studies report that people caring for a person with dementia experience stress and depression.

**Aim:** To explore the scope of communication tools through WhatsApp groups with the help of family support and work.

**Methods:** 82 caregivers (85.4% women) participating in the ALMA Comahue groups were assessed. 70.7% were sons or daughters of people with cognitive impairment.

**Instruments:** Ad hoc survey and ZARIT caregiver burden questionnaire.

**Results:** Overall, the sample scored the impact of supporting a person diagnosed with dementia as moderate to high; most participants reported that WhatsApp groups made it easier for caregivers to share information, advice, and experiences with each other; they considered that it helped close the gap of weekly meetings, without replacing them; WhatsApp groups also present a challenge in adaptation to the use of technological resources. The research provided information on how digital tools, such as WhatsApp groups, can be used to increase communication and assistance between family carers of people with dementia and professionals.



# A Mixed Method Study Exploring Gender Differences in Dementia Caregiving

Mr Vincent Olivier Poisson<sup>1,2</sup>, Dr Roslyn G Poulos<sup>2</sup>, Dr Adrienne L Withall<sup>2</sup>, Ms Ann Reilly<sup>1</sup>, Ms Leanne Emerson<sup>1</sup>, Dr Claire M.C O'Connor<sup>2</sup>, **Dr Kaele Stokes**<sup>1</sup>, **Ms Barbra Williams**<sup>3</sup>

<sup>1</sup>Dementia Australia, Melbourne, Australia. <sup>2</sup>The University of New South Wales, Sydney, Australia. <sup>3</sup>Dementia Australia, Candelo, Australia

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aims:** Few studies have investigated the experience of male carers of people with dementia and fewer specifically examined whether male and female carers of people with dementia differ in their approach to the caring role. As such, this research set-out to investigate whether male carers of people with dementia approach the caring role differently to female carers.

**Method:** Data from 167 survey participants (24 males and 143 females) were analysed using a mixed research methodology. Participants' demographics and scores on standardised burden and coping scales were analysed using linear regression. Participants' written responses to open-ended questions were analysed using thematic analysis anchored in theories of hegemonic masculinity.

**Results**: No significant gender differences were identified in carers' coping strategies or self-reported carer burden. However, qualitative analysis revealed strong thematic gender differences like: gendered barriers to help-seeking; gendered service preference; gendered considerations about residential care; gendered expression of burden; and themes of the absent son and exhausted daughter.

**Conclusion:** This research identified that male carers of people with dementia approach help-seeking differently to female carers, typically focusing on addressing functional tasks and refraining from showing emotions, this despite reporting similar carer burden. Rapport building with male carers should start with conversations around functional issues rather than assessing the emotional impact of the caring role. The findings reinforce the need for more qualitative research into the unmet needs of male carers of people with dementia, to inform the design of male-friendly interventions which could facilitate timely access to services by male carers.



# A study on the stress and social support network of person living with dementia caregivers in rural communities

#### **Prof Wan Jen Chang**

National Chung Cheng University, Chia-Yi, Taiwan

#### **Topic**

Support for dementia carers: Informal carers support - pre, during and post

#### **Abstract**

**Aims:** This study has two main purposes one is to explore the stress of people living with dementia caregivers in the Chiayi County's rural communities, and the other is to explore their stress status after using the social support network from community dementia service bases.

**Method:** This study adopted a qualitative research method and the total of 8 focus discussions were conducted pre- during and post to collect research data within six months. The research subjects recruited 40 persons living with dementia caregivers from 29 rural community dementia service bases in Chiayi County.

**Results:** The results of this study are summarized as follows: 1. Pre-support situation: The living with dementia caregivers cannot effectively adjust their emotions and stress. Due to the factors such as over-dependence of people living with dementia, resistance to taking medications for chronic diseases, abnormal daily routines, the misunderstanding of dementia by neighbors, and the lack of a friendly environment, etc., the caregivers are under physical, psychological and lack of personal time pressure. 2. Support process: The caregiver accompanying the person living with dementia to community dementia service base can exchange care experiences with other caregivers, attend activities or exercise to relieve stress, and obtain financial subsidy resources, which can help to support their care pressure. 3. Post-support situation: Caregivers put forward three social support suggestions to the Chiayi County Government as follows: (1) Establish a learning resource platform for dementia care knowledge and skills. (2) Promote more dementia-friendly places and communities. (3) Provide diversified psychological, emotional and social support for caregivers.

**Conclusion** The social support network provided by the rural community dementia service base can help reduce the physical, psychological and social pressure of caregivers. However, the Chiayi County Government still need to further provide more physical, psychological, and social resources to caregivers.



# Creative writing as a resource for respite, relaxation, rejuvenation and revelation for carers and a segment of the population living with dementia.

#### **Ms Mary Crescenzo**

AlzAuthors, Redmond, Washington, USA. Dementia Map Global Resource, Portland, Oregon, USA

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

Participation in the art of writing through fluid guidance, without judgment, within a safe space for self-expression, and facilitated by arts practitioners in the field of writing and person-centered dementia care, can provide respite, relaxation, rejuvenation and revelation for carers as well as a particular group of persons living with dementia.

My examination of this practice of writing was born out of necessity. As a pioneer arts strategist/ practitioner in the mid-nineties utilizing arts engagement with persons living with dementia, I developed methods to engage in visual art, music, movement/dance, poetry/storytelling to connect and communicate with people I served in various care communities. Driving home after work, I often found myself in tears in response to conditions I observed and the range of attitudes of staff and administrators towards residents. Each evening, to process my feelings, I wrote persona poems in the voices of the residents from observation, imagination, and from random yet profound statements spoken by residents. Writing allowed me to manage my experiences in pursuit of connection and communication with this population. Writing became a resource for self-care - an expressive, cathartic, positive way to release my feelings on paper. Each subsequent day, I was better equipped to foster self-expression and creativity with those I worked with and set the stage for recognition and dignity for this population. Years later, these persona poems developed into a monologue-based play entitled, Planet A, about the inner world of dementia.

In conclusion, I recognized that formal and informal carers and a segment of persons living with dementia could benefit from self-expression through creative writing. I designed and facilitated writing sessions for the above mentioned groups. I continue to facilitate workshop-based programs using open-ended writing prompts and exercises for participants, and provide post-workshop prompts and exercises for sustainability of this practice.



# Technological Interventions in Dementia Care: An Analysis of Usability and Impact on Caregiver Burden.

Ms Tara Harkin, Ms Katie McGuinness, Prof Joan Condell, Mr Tony Robinson, Dr Siobhan Poulter, Dr Matthew Manktelow, Ms Rosemary Bradley, **Mr James Gillespie**, Dr Leigh Johnston, Dr Kurtis Ashcroft Ulster University, School of Computing, Engineering, and Intelligent Systems, Derry, United Kingdom

#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

The escalation of Alzheimer's cases and other forms of dementia underlines the growing demand for informal caregivers. Within the UK, the population was aged 65 and older as of 2019 and is expected to reach 24% by 2043. Similarly, it is suggested that by 2050 over one-third of the EU population will be 65 and older, 5-8% of which are estimated to suffer from dementia. Dementia's status as a global public health pandemic and exponential prevalence with age mean that dementia care can be especially burdensome for individuals and their families. As of 2022, there were an estimated 4.9 million informal carers within the UK. A better understanding of the specific domains of caregiver burden is required so that caregivers may be supported as intervention broadly applied is often ineffective.

In our endeavour to better understand the role of technology in the everyday lives of informal carers, we undertook an extensive mixed methods study evaluating the usability of various forms of technology, including wearables. We followed a cohort of carers in a range of caring roles over a period of 2 years. Participants were given the choice of which technology they use based on their perceived need and interviewed at the beginning and end of the study using the Zarit burden interview (ZBI). ZBI results were analysed using confirmatory and exploratory factor analysis then technology effectiveness was evaluated.

Of the dimensions identified within our study, Impact on Relationships ( $\Delta$ =1.2097,p=0.039), Self-evaluation ( $\Delta$ =1.4032,p=0.0377) and Sustainability of Care ( $\Delta$ =1.0484,p=0.0524) had the greatest difference between the pre and post technology results. While the Zarit burden contains many unique dimensions sensitive to social and cultural nuances, there is clear evidence that interventions to support carers within the community need to be tailored to the specific needs of carers.



# Psychological distress of former family caregivers after nursing home admission of their relative living with dementia: a preliminary study.

Ms Lea-Maude Leblond<sup>1</sup>, Dr Melanie Belzile Lavoie<sup>2</sup>, Ms Megan Sheehan<sup>2</sup>, **Dr Jean Vezina**<sup>2</sup>

<sup>1</sup>Universtiy Laval, Quebec, Canada. <sup>2</sup>University Laval, Quebec, Canada

### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Objective:** Placing a loved one with major neurocognitive impairment in a nursing home can be a source of relief for family caregivers. Still, it can also be a time of many challenges. This study aimed to compare the distress of family caregivers who had recently placed their loved one with those who had not yet done so.

**Methodology:** Three groups of women caregivers were recruited. The first group (n=14) consisted of caregivers who had just started caring for their loved one, the second group (n=14) had applied to place their relatives in a nursing home, and the third group (n=13) had put their relatives in a nursing home for less than six months. Participants completed several questionnaires, including Kessler-10 (K10), which measures psychological distress.

**Results:** Placing a relative in a nursing home relieves caregivers, but results show that distress levels remain abnormally high several months later. We can see that people who have placed their relatives in retirement homes are facing new difficulties. These new difficulties contribute to their level of distress being higher than that observed in the general population for a population of the same age and exceeding the critical threshold.

**Conclusion:** This study shows that even when a person living with dementia is placed in a nursing home, family carers experience significant distress. It would be wrong to assume that their psychological state will instantly improve. Appropriate measures must be implemented to help them transition between home care and nursing home care, reduce guilt, reorganize their lifestyle, etc. Further studies are needed to understand former family carers' specific needs better.



# Digital health interventions and services for informal caregivers of people with dementia: a scoping review of reviews.

**Dr Siti Maisarah Mattap**<sup>1</sup>, Dr Jessica Watterson<sup>2,1</sup>, Mr Tuan Anh Tran<sup>1</sup>, Mr Zen Hui Ng<sup>1</sup>, Miss Hui Jie Teng<sup>1</sup>, Dr Deepa Alex<sup>1</sup>, Prof Tin Tin Su<sup>1</sup>, Dr Aiedah Binti Abdul Khalek<sup>3</sup>, Prof Kit Chan<sup>4,5</sup>, Prof Hoang Van Minh<sup>6</sup>, Dr Duong Minh Duc<sup>6</sup>, Prof Daniel Reidpath<sup>7</sup>, Prof Louise Robinson<sup>8</sup>, Prof Shahjahan Yasin<sup>1</sup>, Dr Narelle Warren<sup>5</sup>, Dr Devi Mohan<sup>1</sup>

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aim:** Dementia progression escalates caregiver dependency, placing a substantial impact on informal caregivers, particularly in regions with limited formal dementia care. Digital health interventions (DHI) present a burgeoning avenue for caregiver support, supplementing traditional face-to-face approaches. We aim to map the large body of reviews on DHI available for or impacting informal dementia caregivers and to identify the current consensus on DHIs' outcomes on caregivers, and the implementations' facilitators and barriers.

**Methods:** A scoping review of reviews was conducted using the Joanna Briggs Institute scoping review method. Our search across various databases yielded 8,704 studies published up to May 24, 2023. Covidence web-based tool facilitated study screening. We included structured reviews and meta-analyses in English focused on DHI for dementia caregivers and caregiver outcomes.

**Results:** Of the 8,704 studies, 100 reviews were included. Most of the DHI studies are from high-income countries. Reviews tend to use broad or umbrella terms (e.g., technology-based, DHI) compared to focused terms (e.g., mHealth) or specific tools (e.g., mobile apps, video-conferencing). Communication, information, and support emerged as prevalent DHI functions for caregivers compared to those for dementia management (ratio 5:2). 80 reviews outlined DHI's impact on caregivers, with 60% emphasising positive outcomes (i.e., better quality of life, health improvement, perceived values), 35% indicating mixed impact, and 4% discussing negative effects (increased burden, poorer or no impact on health (i.e., stress, anxiety)). Various facilitators and barriers of DHI, while ethnocultural linguistic fitness and personalisation of the DHI to meet the users' needs and preferences are some of the important factors of DHI uptake.

**Conclusions:** DHI positively impact dementia caregivers, enhancing caregiving through effective communication, information dissemination, and group support. Future studies should focus on tailoring DHI to caregivers' needs, preferences, and contextual factors, especially in regions lacking ethnocultural linguistic fitness and adaptability of DHI.



# **Dementia Social Support Center - Developing Diverse Support Channels**

Miss Ciao-Yei Chen, Miss Yun-Ching Chen

Taiwan Alzheimer's Disease Association, Taipei, Taiwan

#### **Topic**

Support for dementia carers: Informal carers support - pre, during and post

#### **Abstract**

The Dementia Social Support Center was established in September 2009 with a commitment to providing diverse support channels to assist caregivers in coping with the various challenges posed by dementia. The center's initiatives include counseling services, a national dementia social support website, and family support services, among other diverse support channels. The establishment of a national dementia care helpline offers daily counseling services from 9 AM to 9 PM in the form of toll-free phone calls. It also provides in-person counseling and multiple online counseling channels, including Line, Facebook, and email, to make it convenient for caregivers to choose the most suitable method of consultation. Professional advice and support are readily available. To date, the center has accumulated over 60,000 counseling service sessions, reaching 8,050 sessions in 2022. It regularly updates dementia-related resources and compiles information about resource agencies and services nationwide on the National Dementia Social Support website, with 1,815 entries achieved in the 2022 fiscal year, ensuring that family members and the general public can access the most comprehensive information. The center also organizes physical family seminars and family support groups, providing opportunities for interaction and communication to meet caregivers' needs. These activities help caregivers better adapt to the impact of dementia and collectively address multiple challenges.

In this article will explore the diverse support channels developed in response to caregivers' needs, using the characteristics of the population utilizing the center's services, support requirements, and the relationship of service provision to assist in the development of caregiver support strategies.



# A Support Group for Families with a Member with an Intellectual Disability Who is Living with Dementia: A Case Study and a Story

#### **Ms Kathryn Service**

Mass DDS, Northampton, USA. National Task Group on ID and Dementia, Northampton, USA

### **Topic**

Support for dementia carers: Informal carers support - pre, during and post

#### **Abstract**

Using the lens of a case study, a unique Family Support Group will be examined and together with participants' assistance the story of the group will be shared. In the US support groups have been popular and found to be beneficial for many conditions as well as diverse sets of participants. Here is the story: In 2016 under the auspices of a US based national organization, two family members, a sister and a mother, of men with Down syndrome (DS) started a support group for families who have a member with intellectual disabilities (ID) who is living with dementia, either in or out of the family home. The mother's son had not been diagnosed with dementia; whereas, the sister's brother had already died with Alzheimer's dementia which is a high risk condition for people with DS. It was structured after a common model for families in the ID system using peer support and facilitated by a peer. It meets virtually once a month. The group welcomes members whose family member has died as they offer a lived experience understanding. In addition to time to share experiences, frustrations and solace, Occasional speakers have offered brief educational segments on topics that arise through the conversations. The story continues:

The present facilitator is not a family member as such; rather a nurse practitioner (NP), who was trained as a facilitator through the Alzheimer's Association and carried on the group after the original facilitators left. This person had been asked by sister (as above) to 'help her' when the mother wasn't able to join the meeting; thus understood the culture and cadence of the group. The unique nature of these family relationships, which entail lifelong caregiving and caring is also fully appreciated. It continues as such today.



Exploring the prevalence of carer strain and grief among informal cares of persons living with dementia, measuring carer distress caused by neuro-psychiatric symptoms, and identifying areas where carers may benefit from external support – a study conducted in Chennai, India

Ms Pavithra Gangadharan<sup>1</sup>, Dr Rufus Singh<sup>2</sup>

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

Currently, dementia affects over 8.8 million individuals aged 60+, in India and its incidence is projected to increase significantly, presenting a formidable challenge for informal (family) carers who bear the primary responsibility for providing care.

Findings suggest that informal carers encounter significant levels of strain (physical, social, financial, psychological) and distress (caused by neuropsychiatric symptoms of dementia), as well as difficulties in managing pre-death grief. These experiences can result in adverse outcomes for both individuals living with dementia (including early institutionalisation, reduced quality of life, and increased mortality) and their informal carers (including problems with physical health and mental health (like depression)). In this context, provision of at-home support to carers of individuals with dementia has been found to reduce the burden associated with caregiving responsibilities and enhance the mental well-being of carers.

This study aims to investigate the prevalence of carer burden, carer distress, and carer grief among informal (family) carers of individuals with dementia residing in Chennai, India, and to identify the types of support interventions that these carers perceive as helpful in alleviating their overall burden. The study employs a mixed-method, cross-sectional design and uses questionnaires incorporating validated tools and interviews to capture data. Data collection is currently ongoing and is expected to be completed in December 2023.

Study findings will be presented. Results obtained from this study will provide valuable insights for both clinical and non-clinical providers of dementia-care services in India by informing the design and implementation of service delivery models that effectively address the specific requirements and preferences of informal carers. They may also provide valuable insights for governmental and non-governmental organisations to facilitate the development of awareness programmes and educational material, as well as governmental policies and interventions aimed at enhancing the overall well-being of informal carers of community-dwelling individuals with dementia.



### P46-001

# At Lorenzo's House, we cure isolation, build an alliance and create justice with young people and their families walking with younger-onset dementia

Mrs Diana Shulla Cose, **Mrs Patti LaFleur** Lorenzo's House, Chicago, USA

### **Topic**

Support for dementia carers: Young carers

#### **Abstract**

**Purpose:** At Lorenzo's House, we cure isolation, build an alliance and create justice with young people and their families walking with younger-onset dementia.

**Project Plan:** Through our MATCH program, we connect family members walking with younger-onset dementia. Family profiles guide the process, offering helpful carer criteria to make a wise match– location, family structure, personality, stage of condition, and more. Our Clubs for youth and adults are brave safe spaces to practice mindfulness, exchange common stories, share strategies and build community. We are adding a Shine On group for those whose person/loved one is in their later stages of the condition or has passed. Music, Movement and Community is an in-person interactive experience where music and expression ignite joy held on Chicago's Northside and expanding to the Southside in 2024. Lorenzo's Youth Summit is our annual single day virtual experience that unites children, teens and young adults worldwide, and has been delivered with support from Alzheimer's Society of Canada, Alzheimer's Disease International and London School of Economics. Together, we exchange caregiver strategies, share our common stories, expand brain health knowledge and build our growing youth alliance. Our young professionals from various industries magnify the mission at Lorenzo's House by using their talent and voice to raise awareness.

**Outcomes:** Lorenzo's House families walking with younger-onset dementia feel less alone, a part of a growing alliance of like-minded families and more equipped to care for self and their person/loved one with dementia.

**Conclusions:** Our growing alliance for dementia justice includes more than 1000 family members across 40 states and 8 countries. Hear from Founding Executive Director, Diana Shulla Cose, Patti Lafleur, Lighthouse Lead, our youth, carepartners and facilitators walking this journey united.



#### P46-002

# Training and intervention for carers of individuals with dementia

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## **Topic**

Support for dementia carers: Young carers

#### **Abstract**

The "Insituto de la Memoria" is a foundation located in León, Guanajuato, México which is sustained through donations. It is focused on non-pharmacological treatments for individuals diagnosed with dementia. For their treatment, the institute has a group dedicated to treating mild cases, another for moderate cases, and personalized care for severe cases.

Among the different programs offered by the institute, there is continuing education designed for volunteers as well as formal and non-formal carers. The volunteers come to the institute due to the partnerships with different universities that offer educational programs related to health sciences. This collaboration allows us to welcome approximately 150 students each year, hailing from fields such as psychology, physiotherapy, medicine, nursing, and nutrition. Our institute provides a range of lectures and training sessions to qualify volunteers with the necessary knowledge and skills for working with individuals diagnosed with dementia. These topics include fall prevention, vital sign monitoring, person-centered care, and neurocognitive disorders.

By providing these educational spaces around dementia, we have observed an increased interest in providing care for adults diagnosed with dementia, as well as more empathy arround the challenges faced by both, the diagnosed individuals, and their families.



# P46-003

# The experiences of using respite service in foreign care workers' family caregivers with dementia

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## **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

Dementia is a neurocognitive disorder, accompanied by several behavior and psychological symptoms, which is a great challenge in caring. The caregivers of the person with dementia have insufficient time to rest and their health and quality of life might be affected. Therefore, more and more family caregivers would search the assistance of foreign care workers, and the main role of the caregivers has been shifted to foreign care workers gradually. For protecting their labor rights and human rights, the respite services could be applied since the end of 2018, and both the utilization rate and willingness to use are below 15% so far. Consequently, this study aims to explore the experience of using respite services for family caregivers with dementia who employ foreign care workers and understand their viewpoints on the respite services and how to provide better support them.

Qualitative research method was used in the present study while semi-structures depth-interview was selected as a means of data collecting. Ten caregivers of patients with dementia in northern Taiwan were enrolled.

The study result found that one theme and two main categories were identified from the qualitative content analysis method. The "Desired but unattainable respite" as theme included two main categories: "Respite awareness and needs of family caregivers" and "Insufficient and inadequate service system".

From the research results, we know that family caregivers continue to provide care even if they hire foreign care worker, so the respite needs of both cannot be ignored. However, the current service system still has many limitations. The care models and needs of dementia families should be considered to create more diverse and flexible service plans so that caregivers can get real respite.



# V1-001

#### Acute onset dementia with COVID-19

#### Dr Liybov Pishchikova

Moscow Research Institute of Psychiatry – Branch of the V. Serbsky National Medical Research Centre for Psychiatry and Narcology, Moscow, Russian Federation

## **Topic**

Dementia as a public health priority: COVID-19 and dementia

#### **Abstract**

Mental manifestations of COVID-19 were determined by a wide range of nonspecific psychopathological disorders. They were described previously in infectious diseases as exogenous types of reactions.

**Objectives:** In order to determine the ability of the COVID-19 virus to cause cognitive impairment and dementia in older people, a clinical case of acute onset dementia was analyzed.

#### Methods

- Analysis of a clinical case of acute dementia with COVID-19.
- Review of pathogenesis factors that can cause the development of cognitive dysfunction in COVID-19.
- Drawing a historical parallel with exogenous types of reactions by K. Bonhoeffer.
- Study of psychopathological manifestations of influenza psychoses in the past.

Results: Clinical observation is presented: Woman 64 years old.

Due to overwork, caring for sick parents with COVID-19, sleep deprivation, psychogenics (death of her father from COVID-19), COVID-19 disease (severe bilateral pneumonia with respiratory failure, intoxication, hypoxia, thrombosis), she experienced an acute disorder of cerebral circulation (with damage to the left parietal-temporo-occipital region). Mental disorder manifested itself against this Background:. Asthenia and a depression occurred (as part of the grief reaction). Acute psychosis developed with amentia, agitation, aggression, disorientation, lack of contact with others, confusion, incoherent speech, excitement within the bed. A cognitive deficit was formed, it reached the degree of severe dementia. After 3 months, severe dementia persisted. The patient was transferred to the palliative care unit.

**Conclusions:** Currently, the definition "amentia" is practically not used. The term "delirium" or "confusion" is used. It was described by psychiatrists who studied infectious influenza psychoses in the past. S.S. Korsakov (1891) identified stuporous, delirious, dementia, and abortive forms of amentia. V.P. Serbsky (1912) described asthenic and hallucinatory variants of amentia.

A description of the exogenous type of reactions, including amentia and dementia with COVID-19 is of scientific interest. There are no such clinical observations in existing scientific studies.





# **V2-001**

# Dementia situation in Colombia: Barriers and opportunities

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## **Topic**

**Dementia as a public health priority:** Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

**Aims:** List the barriers to dementia from a public health perspective using information from stakeholders of different groups (academia, community, health care, government) in the country.

Identify the gaps and opportunities to design a dementia plan from a stakeholder perspective.

Demonstrate the importance of stakeholder assessment and their relevance in public health planning

**Methods:** Semi-structured interviews with 12 key stakeholders that included people working in academia, government, and community members to expand how they understand dementia and their related problems and how they can engage with dementia planning in Colombia. Data were analyzed using framework analysis.

**Results:** For participants, dementia does not have the importance it should have and is not a public health priority for the country. There is a lack of community awareness and understanding of dementia, and there is still a lot of stigma and magical beliefs about the condition. There is also a lack of dementia-related services at every care level, a lack of education for healthcare professionals, and a lack of research and characterization of the dementia population in the country. Participants also stated that despite all the barriers mentioned, awareness is growing among the scientific and non-scientific populations, and there are opportunities to lead initiatives that will motivate the government and decision-makers to spot dementia as a public health priority and work on the national dementia plan.

**Conclusions:** Dementia should be a public health priority. Findings contribute to highlighting the multiple barriers that people living with dementia and their families have to face, the lack of community and governmental awareness, and identify the opportunities towards a dementia plan that stakeholders that are in the best position propose to use and translate evidence into public policy and other interventions.



# **V2-002**

# Progress and Functionality of Dementia Specialized Care Hospitals for the Treatment of people with dementia: A Review

Mr Yongil Jeon<sup>1</sup>, Ms Jungrea Lee<sup>1</sup>, Dr Jeewon Suh<sup>1,2</sup>, Dr Imseok Koh<sup>1,2</sup>

<sup>1</sup>National Institute of Dementia, National Medical Center, Seoul, Korea, Republic of. <sup>2</sup>Department of Neurology, National Medical Center, Seoul, Korea, Republic of

#### **Topic**

Dementia as a public health priority: Dementia policy and plans including #WhatsYourPlan Campaign

#### **Abstract**

**Background:** and **Purpose:** As the elderly population rapidly increases and the number of people with dementia is growing, addressing the specialized treatment of patients with Behavioral and Psychological Symptoms of Dementia (BPSD) becomes crucial. Dementia Specialized Care Hospitals are established to provide focused treatment and facilitate patients' return to their local communities for care. This study aims to assess the current status and roles of these hospitals.

**Progress:** Dementia Specialized Care Hospitals are well-equipped medical facilities with trained personnel, necessary infrastructure, and specialized dementia care services. From 2019 to 2022, there were ten Dementia Safety Hospitals comprising 726 beds across sixteen wards. By 2022, these hospitals achieved an occupancy rate of 79.4%, with Alzheimer's disease-related dementia being the most prevalent at 86.3%. Non-pharmacological interventions were administered 6.2 times weekly, and family support was offered 0.9 times weekly. Approximately 24.3% of patients transitioned back to their homes, while 20.1% relocated to long-term care facilities.

**Review of Roles and Functions:** Despite prolonged hospital stays and a discharge rate to other medical facilities at 25.2%, active collaboration with local community care resources is essential to enable patients to reintegrate into their communities post-discharge. Furthermore, establishing a compensation system to expand specialized personnel is pivotal for expanding the network of Dementia Specialized Care Hospitals.



# V3-001

# Exploring Dementia and Neurocognitive Challenges of Migrants from a Moroccan Background:

#### **Prof Mohamed Taiebine**

The Euro-Mediterranean University in Fez (UEMF), FEZ, Morocco

#### **Topic**

Dementia as a public health priority: Dementia, human rights and equitable society

#### **Abstract**

**Aims:** Recent evidence from many countries in Europe indicates that elderly migrants are more prone to certain neurodegenerative diseases. However, cognitive testing is challenging due to language barriers, low education, and/or illiteracy. In the coming decades, this immigrant population will grow older and the incidence of both mild cognitive impairment and dementia will increase accordingly. We present an overview of the sociocultural and linguistic aspects that should be integrated into the neurocognitive testing and dementia care of Moroccan migrants.

**Methods:** By exploring the current literature and navigating clinical practice, a theoretical framework was created to explain the overlap of socio-linguistic and sociocultural aspects between clinicians and Moroccan migrants with neurocognitive disorders in their host countries.

**Results:** The challenges of diagnosis and cognitive-linguistic testing are discussed. A set of recommendations will be formulated for clinicians dealing with cognitive communication disorders in patients with dementia. These recommendations relate to the acculturation and cultural differences between the home country and the countries to which they migrate, which could be similar or dissimilar.

**Conclusion:** Clinicians should be aware of and prepared to address differences in language, culture, ethnicity, and country of origin. Ethnic, linguistic, and sociocultural misunderstandings have been linked to poor linguistic comprehension, language barriers, and poor education. Embracing holistic and culturally tailored dementia care and neurocognitive testing may reduce the phenomenon of under-overdiagnosis of dementia in migrants from culturally and linguistically diverse populations in their host countries.



### V4-001

#### **GENERATIVE WELFARE AND DEMENTIA**

#### **Dr Antonino Riolo**

Asugi, Trieste, Italy

## **Topic**

Dementia as a public health priority: Economics of dementia

#### Abstract

Macroeconomic indicators tell us that the costs of dementia around the world are destined to inexorably grow, determining the issue of sustainability for governments and family members. The average costs of care increase according to the severity of dementia, while family income has not undergone significant changes. The first welfare model envisaged interventions to pay for services such as carers or residential services, while with the second welfare model it is thought that the person with mild cognitive impairment or initial dementia can still be a resource for society. The ability to generate resources on the part of the elderly person with cognitive fragility, who has withdrawn from the productive labor market, pertains to that cognitive reserve that can be made to the social capital of nations more than one might image. In the context of generative welfare, an image is drawn of an elderly person with cognitive fragility who continues to produce goods, no longer according to the logic of the competitiveness of the labor market but as an enrichment for the community in terms of experiences gained and creativity. The indirect costs for the loss of productivity by both patients and their informal caregivers represent the scope of study of our contribution based on which strategies can be implemented not only to reduce these costs but to include people with early dementia in the socio-economic context.



# V5-001

# A Blueprint for Early Detection of Cognitive Impairment: A Roadmap for Global Healthcare System Readiness

Dr Tim MacLeod<sup>1</sup>, Dr Jim Murray<sup>1</sup>, Ms Chantale Bielak<sup>2</sup>, **Dr Katherine J. Selzler**<sup>1</sup>

<sup>1</sup>Davos Alzheimer's Collaborative Health System Preparedness, Wayne, USA. <sup>2</sup>Bridgeable, Toronto, Canada

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

**Aims:** Global healthcare systems are unprepared and ill-equipped to care for the 55 million individuals worldwide affected by Alzheimer's and related dementias. There is a 17 to 20-year gap between clinical innovations and widespread adoption, with less than 50% ever becoming part of real-world practice. Davos Alzheimer's Collaborative Healthcare System Preparedness (DAC-SP) aims to catalyze global healthcare system transformation, providing Alzheimer's patients quicker access to life-changing innovations and therapies. DAC-SP employs implementation science to evaluate programs focused on seeding systemic changes with clear actions and sustainable solutions. Learnings from the initial DAC-SP program on early detection of cognitive impairment were synthesized into a practical digital blueprint, a resource for healthcare systems seeking to modernize Alzheimer's care.

**Methods:** DAC-SP Early Detection Program began in 2021 across seven healthcare system sites in six countries (Brazil, Jamaica, Japan, Mexico, Scotland, and two US sites). The goal was to enhance early detection of cognitive impairment in primary care settings through implementing digital cognitive assessments and a blood-based biomarker test. Over two years, site leaders regularly collaborated on operational and clinical challenges, potential solutions, and co-designed the blueprint.

**Results:** The blueprint distills insights across sites, offering field-tested, practical implementation strategies, essential tasks, resources, and solutions in an accessible format. The blueprint was informed by rigorous cross-site implementation evaluation of the program and was co-designed using human-centered design best practices to ensure the material is highly usable and actionable. Although every system is different, the blueprint allows users to leverage real-world experiences so new innovations and therapies can be applied more efficiently in clinical practice.

**Conclusion:** Establishing early detection programs enhances healthcare system readiness for Alzheimer's care. This digital blueprint serves as an operational roadmap, enabling other healthcare systems to expedite Alzheimer's care transformation so patients and families have access to breakthrough innovations sooner.



## **V5-002**

# Healthcare system readiness for the early detection of Alzheimer's – learning from the Scotland flagship site as part of the Davos Alzheimer's Collaborative global program.

Mrs Alison McKean<sup>1</sup>, Ms Wendy Chambers<sup>2</sup>, Mrs Jacqueline Pike<sup>2</sup>, Prof Craig Ritchie<sup>3</sup>, Dr Alan Duncan<sup>2</sup>, Ms Marian Montanha<sup>2</sup>, Ms Tammie Gottschlich<sup>2</sup>, Ms Jenny Graham<sup>2</sup>, Ms Erin Ritchie<sup>2</sup>

<sup>1</sup>Alzheimer Scotland, Edinburgh, United Kingdom. <sup>2</sup>NHS Dumfries & Galloway, Dumfries, United Kingdom. <sup>3</sup>Scottish Brain Sciences, Edinburgh, United Kingdom

#### **Topic**

Dementia as a public health priority: Healthcare system readiness

#### **Abstract**

**Aims:** Brain Health Scotland was established in 2020 as part of a Government programme to reduce the incidence of dementia across Scotland and to lead and influence change in healthcare. A partnership was formed with a National Health Service site (NHS Dumfries & Galloway) to help understand how equipped current healthcare systems in Scotland are for early detection of Alzheimer's and what is needed to enable this further. This is one of seven sites across the globe working together to surface and share learning.

**Method:** A quality improvement approach was undertaken with multiple partners across the system to test the feasibility and acceptability of new tools (a digital cognitive assessment and a blood based biomarker (BBM)) into clinical pathways in primary care and specialist settings. The work benefitted from incorporating the voice of lived experience with support to promote the benefits of early detection from members of the Scottish Dementia Working Group and care partners. Learning was captured throughout the project in a range of ways including clinician interviews, participant questionnaires and focus groups. Emerging learning was shared at a regular DAC community of practice.

**Results:** Data collection is concluding and we will share the challenges, strategies to overcome, and successes encountered whilst implementing this project[w1] in healthcare systems which are already under pressure. Examples of challenges include practicalities around BBM implementation and successes include increased staff knowledge around brain health and conversations with patients in relation to this.

The quality improvement approach and key relationships in enabling this work will be explained.

**Conclusion(s):**The findings are informing global learning, the national work of Brain Health Scotland and local practice and pathways. The work has included a focus on general population awareness and the importance of public health and has enabled ongoing future focused conversations and potential developments.



# Childhood Dementia - the facts, symptoms and lived experience

Ms Gail Hilton, Ms Megan Maack, Dr Kristina Elvidge

Childhood Dementia Initiative, Sydney, Australia

## **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Introduction:** This presentation will explore what childhood dementia is, the symptoms children and young people experience and statistics associated with it. Through a series of videos, families share their experience and talk about what they need from the health system. The materials presented in this workshop have been developed with funding from the Federal Government and are informed by a burden study prepared by THEMA Consulting: Childhood Dementia in Australia.

**Background:** Childhood dementia is an umbrella term encompassing 70+ rare and ultra-rare genetic conditions. When considered collectively these impact 1 in 2800 live births and result in more than 90 premature deaths per year in Australia. For comparison, there are 92 deaths per year in Australia from cancer in children aged 0–14 (Australian Institute of Health and Welfare, 2020). Until recently, these 70+ conditions have been considered individually, with little recognition, research or support. Collectively addressing childhood dementia provides the opportunity for greater scale, impact and improvement of both services and therapy development.

#### Aims/Objectives: The audience will:

- Understand what childhood dementia is, its causes and symptoms;
- Understand that when considered together, the disorders that cause childhood dementia cause a relatively high proportion of paediatric deaths;
- Gain further insight into the progressive nature of the condition and the wide reaching impacts of dementia on children and their families;
- Consider how services can more appropriately meet the needs of childhood dementia consumers.



Creating a Dementia Inclusive Generation: Lessons learned from Irish Post Primary Schools. Raising awareness of Dementia and its impact not only on the person living with Dementia but their family members and carers, to change attitudes and diminish stigma ultimately creating a more Dementia friendly and inclusive generation and society

#### Ms Cathryn O'Leary

Dublin, Dublin, Ireland

## **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

Statistics show that one in three young people will know someone with dementia (Chirico et al. 2021). The Creating a Dementia Inclusive programme is designed and delivered by The Alzheimer Society Of Ireland (ASI) to increase the awareness and understanding of dementia and help combat the stigma associated with the condition. Changing attitudes and building knowledge can help to reduce the loneliness and social isolation that many people with dementia experience. Targeted at post primary schools and students, the programme empowers a greater understanding of the impact of dementia on not only the People Living with Dementia ( PLWD) but also the impact on family members and carers/ supporters. Students learn how they can develop and maintain supportive and positive relationships with PLWD.

There are two learning elements to this Programme – "The Brain" e-learning module and "The Peer Educator" Programme". The e-learning programme has five areas of learning:

- Growing Older
- About the Brain
- A Healthy Brain
- What is dementia?
- Perceptions of dementia

The aim of the peer education programme is that students will educate others across their community, ultimately raising the profile of dementia, and help eliminate the stigma surrounding dementia. The programme, designed in collaboration with Dementia Services Information and Development Centre , is designed to supplement and build on the knowledge that students are gaining from their normal school lessons.

"Creating a Dementia Inclusive Generation" reaches far beyond being an educational programme for young people; The ASI is an official Challenge Partner of Gaisce, which is the Irish President's prestigious Award for self-development for young people.

At The Alzheimer Society of Ireland one of our long-term strategic objectives is to tackle the stigma associated with dementia in Ireland. Our presentation will highlight how we can do this, through the education sector, helping to "Create a Dementia Inclusive Generation".



#### LA VOZ DE ALMA RADIO PROGRAM

#### Mr Guillero Ferro

Asociación Lucha contra el Mal de Alzheimer y Alteraciones semejantes de la República Argentina (ALMA), Buenos Aires, Argentina

## **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### Abstract

#### LA VOZ DE ALMA RADIO PROGRAM

This project is based on the experience of the Asociación Lucha contra el Mal de Alzheimer y Alteraciones semejantes de la República Argentina (A.L.M.A.). We understand that it is necessary to talk about dementia, to address the media, to communicate and raise awareness, and to reach more people who need to know about the disease. There are many families who need to hear professionals talk about dementia, hear other stories of families who live with it, and understand that they are not alone and that there are many who are going through or have gone through similar situations.

The project disseminates ALMA's work and services through a public radio program. It informs the general audience about dementia and delivers data on ways to delay the progression or prevention by addressing modifiable risk factors. The program also raises awareness of dementia, addresses stigma, and encourages people to seek more information, advice and support.

**Target Audience:** General public. According to reports and statistics, in Argentina it is estimated that one in eight adults over 65 has dementia, and that there are more than 500,000 people in the country who suffer from it.

This one-hour weekly radio program is informal, relaxed and informative. Two hosts provide information, statistics, testimonies, life stories, studies, reports, experiences and share music. Each program includes interviews with people, personalities and professionals related to the subject.

12 programs were produced during 2022 and 15 during 2023.

Programs are broadcasted on 1920 Los Locos de la Azotea - Radio Online (https://1920live.com/) and then uploaded on the A.L.M.A. Youtube channel (https://www.youtube.com/@a.l.m.a.asociaciondeluchac3588/videos).



# Development and psychometric performance of the Dementia Awareness and Friendliness Survey (DAFS)

Prof LI-JUNG ELIZABETH KU<sup>1,2</sup>, Prof Su-Pin Hung<sup>1</sup>

<sup>1</sup>National Cheng Kung University, Tainan, Taiwan. <sup>2</sup>UNSW, Sydney, Australia

#### **Topic**

Dementia awareness: Attitudes, awareness and stigma

#### **Abstract**

**Aims:** The second action area of the global dementia action plan was dementia awareness and friendly attitudes, but currently there is no tool to evaluate those two outcomes together among the general public. This study aimed to develop a new tool, the Dementia Awareness and Friendliness Survey (DAFS), and to examine its psychometric performance among the populations in Taiwan.

**Methods:** The DFAS was developed in two steps. First, the study combined the Shortened Dementia Knowledge Assessment Scale (DKAS-s) and the Dementia Attitude Scale- Chinese version (DAS-C) to form the first survey. Then the 23-item DFAS was developed based on results from item analyses and item response theory (IRT) analyses using data collected from a convenient sample (N=236). Secondly, the psychometric properties of the DFAS were validated by another sample who responded online (N=655) including infit and outfit mean square errors (MNSQ), item separation reliability (ISR), person separation reliabilities (PSR), and instrument reliability.

**Results:** Two-dimensional Partial Credit Model was used to assess the model-data fit, and results exhibited good fit with two dimensions of the DFAS, dementia awareness and friendly attitude. Most of DFAS items also had acceptable infit and outfit MNSQ ranging from 0.7 to 1.3. The ISR of the DAFS was 0.997, and the PSR of dementia awareness and friendliness was 0.667 and 0.885, respectively. The Cronbach's coefficient of the overall DFAS was 0.824.

**Conclusion(s):** The psychometric performance of the 23-item DFAS indicated that it is a valid and reliable tool for assessing the public's awareness and friendliness toward dementia in Taiwan.



# V7-001

# Activities to promote awareness of Alzheimer' disease in Thailand

Prof Nuntika Thavichachart<sup>1</sup>, Mr Prathan Rutchatajumroon<sup>2</sup>

<sup>1</sup>The Alzheimer Foundation of Thailand, Bangkok, Thailand. <sup>2</sup>Thailand Center of Excellence for Life Sciences, Bangkok, Thailand

## **Topic**

**Dementia awareness:** Community partnerships / Public-Private-People partnerships

#### **Abstract**

Raising awareness of Alzheimer's disease in Thailand, many activities have been launched through The Alzheimer Foundation of Thailand (AFT). These activities included joint operations between the public and private sectors and people partnerships. The AFT, a nonprofit organization, has been established since 2008. The objectives are to help the society realize and become aware of AD and to be a focal point for sharing knowledge in Thailand. Some activities will be shown as examples:

- 1) "Bangkok Memory Screening Day" was a two-stage community survey using primary health care strategy and basic health services system to find out the prevalence of cognitive impairment among the elderly aged over 60 in Bangkok Metropolitan. The project's objectives are also to build public awareness of memory screening and improve KAP on AD. We work together with 69 public health centers and their personnel. We screened more than 8,000 elderly and found dementia at 10.3%, MCI at 11.2%, and the conversion rate from MCI to dementia was 12% per year.
- 2) We have organized a yearly workshop for 15 years for preventive strategies. Each year there were more than 300 participants attended. We call the workshop "The School for Aging," which comprised six classrooms: physical exercise, brain exercise, nutrition classroom, music therapy, stress management, and digital media learning for the elderly. The evaluation from the participants was satisfied more than 85 %.
- 3) For implementing preventive activities, The AFT has held a "Psycho-education workshop for caregivers of AD patients" every year for 15 years. We developed many tools to support brain training, such as. 1. "Memo-O-Ke," a DVD karaoke with some lyrics missing to train memory. 2. "Cognitive training cards" cards match games in different dimensions. 3. "Smartphone application," an application that helps the brain according to the elements of cognition, etc.



# V8-001

# **Building Dementia Friendly Community in South Korea: Operating System and Case Examples**

**Ms Eunjung Cho**, Ms Yoonkyung Jung, Dr Jeewon Suh, Dr ImSeok Koh Natioanl Institute of Dementia, National Medical Center, Seoul, Korea, Republic of

#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

The Dementia Friendly Community, funded by the National Dementia Management Program since 2019, aims to create safe, dementia-friendly regions. Its goal is to provide dementia patients and families with secure, community-driven environments, free from the fear of dementia. This initiative showcases the Dementia Friendly Community's operational system and highlights service examples achieved through community collaboration.

The operation of Dementia Friendly Communities involves five stages. First, regions are selected based on assessment by local dementia centers considering factors like the number of patients and local resources. In the second stage, an advisory committee, including local institutions, businesses, and families of patients, gathers input from Dementia Friendly Community. Subsequently, communities receive designation (stage three), followed by operational approval (stage four). During this phase, the focus shifts to education, promotion, building dementia safety networks, implementing programs, and creating dementia-friendly environments. Finally, an annual results report is prepared (stage five).

As a case example, one aspect of Dementia Friendly Communities includes enhancing the response system for missing dementia patients through collaboration with local post offices, police stations, and taxi companies. This partnership has established a robust notification and response system for locating missing dementia patients. Additionally, home visitation programs for patients have been activated, offering 1:1 cognitive enhancement programs and companionship services provided by healthcare professionals and trained volunteers.

The Ministry of Health and Welfare, along with the National Institute of Dementia, remains committed to building dementia-friendly communities in the future.



## V8-002

# Republic of Korea National Dementia Awareness Improvement Project: Dementia Partner Program-Efforts to Promote Participation in Dementia Partner Activities-

Ms Euna Choi<sup>1</sup>, Mr Yong Bok Kim<sup>1</sup>, Dr Jeewon Suh<sup>1,2</sup>, Dr ImSeok Koh<sup>1,2</sup>

<sup>1</sup>National Institute of Dementia, National Medical Center, Seoul, Korea, Republic of. <sup>2</sup>Department of Neurology, National Medical Center, Seoul, Korea, Republic of

#### **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

To create a dementia-friendly community where patients can live comfortably, public interest, understanding, and involvement are crucial. Since 2013, the National Institute of Dementia Center has provided dementia awareness education for the public and operated the "Dementia Partner" training program, promoting empathy for dementia patients and their families. They've also trained "Dementia Partner Plus" volunteers who receive extra education and engage in dementia-related volunteer work. Currently, they've trained 1.6 million Dementia Partners and 230,000 Dementia Partner Plus volunteers.

In recent years, the National Institute of Dementia Center has taken steps to boost Dementia Partner activities in 2023. They now require in the guideline that Dementia Partner Plus participants to actively participate in dementia-related volunteer work after completing their education. They've also enhanced the content of Dementia Partner Plus education, focusing on practical knowledge needed for dementia-related volunteer activities and creating video materials for online accessibility. Additionally, they've recognized and promoted outstanding Dementia Partner activities through a competition, awarding contributions from Dementia Partners and planning to share these examples nationwide. Furthermore, they've developed a "Dementia Partner Activity Showcase" booklet, highlighting activity examples from Metropolitan/Provicial Dementia Centers and Local Dementia Centers, to assist in the operation of the Dementia Partner Program.

Looking ahead, the National Institute of Dementia Center aims to create tailored Dementia Partner education materials for different age groups, expand in-person and online dementia-related volunteer activities, and redesign their website for easier public access, strengthening the Dementia Partner program's foundation.



# V8-003

Improving accessibility of air travel for people living with dementia and their travel companions: What constitutes best practice in dementia awareness and support training outside of the field of healthcare?

Dr Katherine Turner, Dr Alison Warren, Mr Ian Kenneth Grant Sherriff

Plymouth University, Plymouth, United Kingdom

## **Topic**

**Dementia awareness:** Dementia friendliness and inclusivity

#### **Abstract**

Prior to the Covid-19 Pandemic, United Kingdom (UK) special assistance services within air travel were seeing increased demand. Additionally, people with non-visible disabilities like dementia were becoming more aware that they could not only request such services, but that they had a right to request them.

Through advocacy from the authors of this abstract, and organisations such as the UK Prime Minister's Dementia Challenge Group for Air Transport, UK airports and airlines were beginning to recognise and respond to their responsibilities to provide accessible air travel for all passengers, and not just those passengers with an overtly physical disability.

As aviation seeks to recover from the pandemic, it is the authors' view that a dementia focussed training package is urgently needed. This presentation will outline the key findings of a realist synthesis which sought to identify what constitutes best practice in dementia awareness and support training outside of the field of healthcare. By utilising a realist methodology, the synthesis not only identified what works in such training, but in what circumstances and why, so any aviation training package could be built on these principles.

The realist synthesis identified several key mechanisms that should be included within a future training package for the aviation sector. These included (amongst others) the vital importance of including people with lived experience of dementia in the design and delivery of the training to raise awareness and to reduce stigma; the importance of engaging and empowering change agents across aviation; and the practical strategies that can help aviation staff embed what they have learned within their everyday interactions.

Using the findings derived from this research, the authors plan to develop a context specific training package for aviation to enable staff to support passengers living with dementia and those who travel with them in the future.



# V9-001

# The Association of Nutritional Status and Regional Brain Blood Perfusion with Neuropsychiatric Symptoms and Its Subtypes in Alzheimer's Disease Continuum: A Prospective Longitudinal Cohort Study

Dr Jiwei Jiang, Dr Wenyi Li, Prof Jun Xu

Beijing Tiantan Hospital, Capital Medical University, Beijing, China

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

#### **Abstract**

**Aims:** To investigate the associations between baseline and long-term nutritional status and the regional cerebral perfusion with subsequent changes in neuropsychiatric symptoms (NPS) and its subtypes in patients with Alzheimer's disease (AD) continuum.

**Methods:** Totally, 435 participants {285 with NPS, 89 without NPS and 61 HCs} were included from May 1, 2021 and April 30, 2023. Regional cerebral perfusion was evaluated by the corrected cerebral blood flow (cCBF) from the 7-delay pCASL. GLMMs were used to examine the association of baseline and longitudinal nutritional status and cCBF with the changes in the general or specific domain NPI scores after adjustment.

**Results:** During the (8.79±4.11) months follow-up, patients at risk or presence of malnutrition at baseline were significantly associated with subsequent increase in the Neuropsychiatric Inventory (NPI) scores of general NPS (P=0.020), depression (P=0.004), apathy (P=0.048) and appetite/eating disturbances (P=0.002). Baseline increasing cCBF of left putamen (P=0.001) and right VTA (P<0.001) were associated with subsequent deterioration of apathy, while increasing cCBF values of left hypothalamus (P<0.001) and right VTA (P=0.016) were associated with deterioration of appetite/eating disturbances. The longitudinal decrease of MNA score was significantly associated with the increase NPI score of general NPS (β=-0.685, P=0.013), depression (β=-0.147, P=0.003), anxiety (β=-0.126, P=0.009), apathy (β=-0.149, P=0.012) and appetite/eating disturbances (β=-0.116, P=0.001).

**Conclusions:** Baseline and long-term poor nutritional status, and baseline hyperperfusion in dietary nutrition-related brain areas (putamen, VTA, and hypothalamus) can independently predict the deterioration of NPS and its sub-types in patients with AD continuum.



# **V9-002**

Natural Waking; A more flexible and supported breakfast period and the impact on episodes and severity of BPSD and nutritional intake in dementia inpatient care.

#### Mr Philip Addicott

Cardiff & Vale UHB, Cardiff, United Kingdom

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Behavioural and psychological symptoms of dementia

#### **Abstract**

**Background:** Due to a combination of physical and cognitive impairments, people living with Dementia have an elevated risk of developing malnutrition. Hospital wards, historically have very structured personal care and mealtime routines.

Natural waking is based on the concept that having a more flexible breakfast service, allowing people to wake up naturally can increase restful sleep, aids orientation and improves appetite; people wake up happier and less stressed.

A potential downside is that people sleep through breakfast and miss an important opportunity to eat and drink. To address this, our initiative includes the novel role of a ward based "Natural Waking Technician" who ensures people who sleep in, can access food & drink and are not nutritionally disadvantaged.

**Methods:** A comprehensive literature search identified an absence of research on how introducing such an initiative can reduce episodes of BPSD whilst avoiding a deterioration in nutritional status.

To test for changes in levels of BPSD, the Neuropsychiatric Inventory Questionnaire is a validated tool for assessing change in neuropsychiatric symptoms. The presence and severity of BPSD, measured pre and post introduction of natural waking.

To offer insight into the impact of natural waking on inpatients and their nutritional status, a questionnaire (for inpatients, staff and family) also an inpatient case study and weekly body weight measurement are considered.

**Results:** Natural Waking, with a more flexible breakfast service supported by the Natural Waking Technician, has reduced frequency and severity of BPSD whilst maintaining nutritional status. This person-centred approach meets the needs of people living with dementia and places nutrition and hydration in the spot light.

**Conclusion:** A more flexible and supported breakfast period and allowing people to wake naturally is advocated for people living with a dementia. This approach promotes a calmer environment and initial findings from our service improvement project are promising.



# Harnessing Consumer-Grade EEG Data as a Neurophysiological Biomarker for Cognitive Impairment Assessment

Ms Rosmary Blanco, Dr Alessandro Crimi

Sano Centre for Computational Medicine, Krakow, Poland

#### **Topic**

Dementia diagnosis, treatment, care and support: Biomarkers

#### **Abstract**

Early diagnosis of dementia is crucial for effective treatment planning. Traditional methods like cognitive tests can lead to misdiagnosis, particularly in the early stages. Structural biomarkers like cerebrospinal fluid (CSF) and positron emission tomography (PET) scans are invasive, costly, and have limited availability. EEG biomarkers are cost-effective, offering objective neural activity measurement. Event-related evoked potentials (ERP – P300) are valuable for dementia assessment, including Alzheimer's disease (AD). However, they haven't translated into clinical tools. Modern neurotechnology and state-of-the-art learning algorithms can contribute to improving computer-aided diagnosis of dementia in daily life.

We introduce an empirical tool within the EEG-based passive P300 application framework to identify EEG-based features that differentiate between Mild Cognitive Impairment (MCI), moderate AD, other forms of dementia, and cognitively healthy elderly individuals. This tool is designed to assess how emotional stimuli of different valences can impact the modulation of visual attention. Its primary objective is to assess cognitive impairment using classical neurophysiological metrics (P300 latency and amplitude) and apply machine learning models for differentiation.

The study is expected to identify specific EEG-based biomarkers related to cognitive impairment, understand how EEG responses vary across these different groups aiding the differential diagnosis of subjects with dementia, and validate machine learning's effectiveness using wearable EEG data to distinguish between various forms of dementia. This potential achievement represents a substantial stride toward the development of more accessible and cost-effective diagnostic tools.

Despite the absence of concrete results at this stage, this study can provide valuable insights into the emotions on the modulation of visual attention and its connection to neural activity and cognitive impairment. Additional data collection, analysis, and validation are essential. The introduced empirical tool underscores the promising role of EEG-based features as a valuable neurological index for the diagnosis of AD and high-risk subjects who might develop dementia.





# "Its the little things": promotion of relational care and social health using creative activities.

Prof Victoria Tischler<sup>1</sup>, Dr Chloe Asker<sup>1</sup>, Dr Hannah Zeilig<sup>2</sup>, Dr Mary O'Malley<sup>3</sup>

<sup>1</sup>University of Surrey, Guildford, United Kingdom. <sup>2</sup>University of the Arts London, London, United Kingdom. <sup>3</sup>University of Worcester, Worcester, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Aims:** Deprivation and distress were commonly experienced by those with dementia in care homes during the COVID-19 pandemic. Remote and digital creative activities were designed and delivered as 'Culture Boxes' to care homes, aiming to address the social isolation and loneliness experienced by people with dementia, and to support care staff working with them.

**Method:** Participatory Action Research was used to assess the impact of the Culture Box project. Baseline and follow-up surveys and dialogic interviews at 3 time points during the study collected qualitative data that was analysed descriptively and via inductive thematic analysis respectively.

**Results:** Eighty-eight people with dementia and 33 care staff from 33 care homes across England were recruited to the study, with 68 people with dementia and 28 staff completing the study 12 months later. Qualitative findings indicated that the project activities facilitated relational care through creative experiences characterised by sharing, building relationships, and developing a sense of community. Social health was promoted via participation in social activities and fostering independence.

**Conclusions:** Creative activities support the development of relational dementia care, i.e., care that is trusting, reciprocal and mutually beneficial, for those with dementia and care staff. Socialisation and independence in people living with dementia can be fostered using engaging and interactive creative methods. Future studies should explore the utility of creative practices to develop relational care, to support care staff, and to maximise wellbeing benefits for those living with dementia in a variety of settings.



Care through the arts: how the arts can foster connection and communication to enrich the lives of those living with dementia and their carers.

#### **Ms Mary Crescenzo**

AlzAuthors, Redmond, Washington, USA. Dementia Map, Portland, Oregon, USA

## **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

Person-centered care through a multidisciplinary, multigenerational approach utilizing arts engagement can be a catalyst for self-expression through creative response, whether representational or abstract. Introduction of various art forms in a welcoming environment on a regular basis, through fluid guidance and a person-centered approach can provide stimulation, mobility, socialization, and relaxation, and foster complementary connection and communication between a person living with dementia and those who care for them. With a focus on open-ended, non-judgmental, process-based art experiences, arts engagement allows for the preservation of dignity and improved quality of life for persons with this condition, formal and informal carers, family and friends.

Through described methods and techniques, anyone can engage with a person living with dementia through music and song, drawing and painting, movement and dance, and storytelling and poetry at various stages of dementia. This multidisciplinary arts approach for arts engagement can be enhanced by a multigenerational presence. The arts draw upon creativity, self-expression and emotion, often stimulate memory and articulation during an art experience, and provide common ground for expression, whether in collaboration, or in celebration of the unique act of creativity in the person living with dementia. Artistic training or what may be referred to as artistic talent, are not prerequisites for the ability to present or collaborate in an arts experience with a person living with dementia, nor does the person with this condition need to have had a heightened ability to create art or experience the arts.

The author's pioneer arts engagement work since the mid-nineties as arts strategist and arts practitioner is the foundation for this presentation, as well as her publication, The Planet Alzheimer's Guide: 8 Ways the Arts Can Transform the Life of Your Loved One and Your Own. The author is also the founder of Care Through the Artssm.



# Assessing the Feasibility of Pastel Nagomi Art Program for Elderly Individuals living with Dementia and Mild Cognitive Impairments

#### **Ms Wanching Peng**

Taipei City Hospotal, Taipei, Taiwan

#### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

Many prior studies have demonstrated the therapeutic efficacy and high applicability of art therapy for elderly individuals living with dementia. Pastel Nagomi Art originating from Japan involves applying pastel powder to paper using fingers, without the need for specialized drawing tools or artistic experience. It is accessible to individuals of all ages, and the creative process has been associated with feelings of calmness, relaxation, focus, and a sense of achievement. Researchers designed a series of 16 sessions of Pastel Nagomi Art program and applied them to two people diagnosed with dementia and thirteen individuals living with mild cognitive impairment, aiming to assess the feasibility of Pastel Nagomi Art program for seniors with cognitive impairments by observing participants' engagement, attention span, completion of artwork, and creativity during the sessions.

After 16 sessions, the attendance rate was approximately 80%, with all attendees successfully completing their artwork. Participants exhibited an attention span of over 30 minutes, and in the later stages of the program, they demonstrated increased initiative in starting and completing their artworks, as well as greater autonomy in choosing colors and subject matter.

Based on these findings, it can be inferred that there is feasibility of Pastel Nagomi Art program for both people living with dementia and mild cognitive impairment.



# Utilizing Integrated Record Forms to Enhance the Effectiveness of Group Activities in Community-based Dementia Service Stations

Ms Chia-Hui Lin<sup>1,2</sup>, Ms Hsiu-Yang Hung<sup>1,3</sup>, Ms Huei-Ling Huang<sup>1</sup>, Ms Tsui-Mi Huang<sup>4</sup>

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## **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Aims:** Providing well-planned group activities for persons with dementia can promote social participation, delay functional deterioration and improve the quality of life. Evaluation before and during group activities is the key to success. The purpose of this project is first to understand the situation of group activity leaders in conducting assessment before and observing during the group activities. Next, to develop an intervention program to provide individualized group activities that meet the needs of the persons with dementia.

**Method:** This project was conducted in northern Taiwan. In the first phase, data analysis was conducted on the assessment results of 29 community-based dementia service stations to identify problems and needs, and on-site observations and interviews were conducted at six service stations. In the second phase, based on the results of the previous analysis, the "Integrated Pre- Activity Assessment and Group Participation Record Form" intervention program was implemented. The intervention measures included: implementation, development of instructions for the use of the form, and organization of educational trainings.

**Results:** Results of the first phase showed that the 29 service stations only attained 62.3% of full compliance in the item of "activity planning and implementation", which was the lowest score among all indicators. Interviews showed that some of the service stations did not conduct assessments before activities, did not make any adjustments based on individuals' abilities, did not hold pre-session meetings, and had incomplete records of pre-session assessments and activity logs. In the pilot test, 95% of the group activity leaders who participated in the intervention program were able to use the integrated form correctly, and their satisfaction level with the integrated form reached 90%.

**Conclusion:** The results of this study can be used as a reference for the future planning and implementation of programs at the community service sites for dementia.



# To study the feasibility of delivery of virtual Montessori-based cognitive stimulating activities for older adults with dementia in the community.

Miss Suet Lai Leung, Mr Gabriel Yeung Caritas-Hong Kong, Hong Kong, Hong Kong

## **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Aim:** This study aims to explore the feasibility of delivering Montessori-based cognitive stimulating activities for older adults with dementia via the online platform.

**Method:** Participants were recruited from the "Enhanced Home and Community Care Services for Frail Elderly" in Hong Kong from September 2022 to August 2033. The inclusion criteria were: (1) aged 65 or above, and (2) had a primary diagnosis of dementia. Those who were unable to follow commands were excluded. Based on the principles of DementiaAbility

**Methods:** The Montessori Way, Occupational Therapists (OT) designed the 24-session (twice per week) cognitive stimulating program for participants to maintain or delay the decline of their cognitive function. The program comprised reality orientation, reading task, brain gym exercises, and graded cognitive training games, and was delivered by OT via Zoom Meetings. The Cantonese Version Hierarchic Dementia Scale (CV-HDS) was administered before and after the training. The participants' and their caregivers' satisfaction were evaluated using the modified Telemedicine Satisfaction Questionnaire.

**Results:** Seven participants (female=5) were recruited with a mean age of 81.43+6.63 years. The mean total score of CV-HDS was 155.29 at baseline. The Wilcoxon-signed rank test showed that there was a significant increase in the CV-HDS score after training (p=0.034). In the user satisfaction questionnaire (n=7), six respondents reported that technical assistance was required in joining the online program. All respondents agreed or strongly agreed that online program was convenient and saved travelling time, and training content was appropriate to their needs.

**Conclusions:** This study supports the implementation of virtual Montessori-based cognitive stimulating activities for older adults with dementia in the community with fewer restrictions on distance and time. Telerehabilitation programs may be a solution to answer the immense service needs. Future studies should recruit more participants and adopt a more rigorous study design.



# Home-based Music Therapy for Persons with Young-Onset Dementia: A Case Study

#### Ms Evelyn Lee

Prospect Music Therapy, Singapore, Singapore

#### **Topic**

Dementia diagnosis, treatment, care and support: Dementia therapies (Music, dance, art etc.)

#### **Abstract**

**Aim:** This study aims to evaluate the effectiveness of a music therapist-administered protocol designed to engage family members in the care of individuals living with dementia.

**Method:** Employing a retrospective case note study, the study investigates a comprehensive music protocol comprising a family interview, homework assignments, and strategies to empower family members for sustained active musical engagement with the person living with dementia.

**Result:** Caregivers reported an increase in overall satisfaction and a notable reduction in stress levels following the implementation of the music protocol.

**Conclusion:** The findings of this study suggest that a structured music therapy protocol, when administered by a trained music therapist and involving family members, can have a positive impact on dementia care. Specifically, caregivers experienced a boost in their sense of satisfaction and a decline in stress levels. These outcomes imply that the music therapy protocol can benefit not only the individuals living with dementia but also improve the well-being of their caregivers. Further research is recommended to substantiate these findings and to investigate the long-term benefits and scalability of this approach in dementia care.



# V11-001

# Spiritual journey in the ageing and journey with dementia: a case study

#### **Prof Merle Varik**

Tartu Health Care College, Tartu, Estonia

## **Topic**

Dementia diagnosis, treatment, care and support: Dementia, dignity and spirituality

#### **Abstract**

**Background:** Allen and Coleman (2006) describe spirituality as essential nature to human beings and as internal force. The ways to expresses spirituality can be different, for example, one of them is religion, also meaningful life. For the people with dementia the spirituality can relate to hope, safety and to be loved. Holistic care and person-centredness consist therefore of an individual's physical, psycho-social, and spiritual needs and of skilful care and respecting the needs of the person.

**Aim:** describe the spiritual care nature in perspective of person who living with moderate dementia in the nursing home.

**Methods:** The case study carry out from January to September 2023 when appeared that independent living at home was not anymore possible and the person moved into nursing home. Three unstructured interviews and 6 informal interviews were carried out. The case study contains the vignettes setting out the situations.

**Results:** Moving into nursing home not easy. The most important were for person with dementia that the staff and also the other residents respect her needs and desires; family members keep the touch and support her; that she has opportunity to share her life story; and during the ADL she has secured privacy. It was also essential to being socially involved and able to continue with her hobbies (singing, walking, watching TV) and attend a church service. Conclusion Satisfying spiritual needs is essential for ensuring well-being, adapting to a new environment and people



# V12-001

# Can the Remedes for Alzheimer's battery (R4Alz-R) replace the classic neuropsychological tests for the diagnosis of minor neurocognitive disorders? Examining the battery's construct validity

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Introduction:** R4Alz-R is a novel tool utilized for the early detection of minor neurocognitive disorders, (SCD-MCI), designed to assess working memory, cognitive/attentional control, cognitive flexibility, visual/verbal memory, planning, and visual fluency. Objectives: To assess the battery's: a) construct validity, b) predictive validity against the activities of daily living (ADL) and, c) convergent validity with the criterion standards of neuropsychological testing, developed to measure the respective abilities.

**Methods:** The study comprised 404 people, categorized as healthy adults (n=221), people with SCD (n = 74), and people with MCI (n = 109). The neuropsychological tests utilized to infer the convergent validity, comprised tests evaluating working memory, cognitive control abilities, verbal/visual memory, and a functional assessment for the evaluation of the predictive validity.

**Results:** A two-factor model of the R4Alz-R battery was confirmed, comprising abilities of a) fluent intelligence/working memory (FI/WM), and b) executive function (EF). The total score of the R4Alz-R battery predicts daily functioning, whilst significant correlations between all tasks of R4Alz-R and the tests utilized as external criteria, were revealed.

**Conclusions:** a) the R4Alz-R presents a high internal consistency between its tasks and subtasks by primarily evaluating FI/WM and EF, b) it involves and requires additional secondary cognitive abilities, c) it can directly predict EF and ADL, and d) has excellent psychometric abilities, thus it can be used in all the clinical settings for detecting cognitive deficits and can replace other cognitive tests administered separately in the diagnostic procedure.



#### V12-002

# EBC Rethinking Alzheimer's disease: Cross-roads in the earlier detection and diagnosis of Alzheimer's

#### **Prof Charlotte Teunissen**

Amsterdam UMC, Amsterdam, Netherlands

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### Abstract

Alzheimer's disease (AD), the most common form of dementia, is a progressive and debilitating neurodegenerative condition which robs people of their memory, their independence, their relationships and, ultimately, their lives. It affects close to 7 million people in the European Union (EU) alone.

The detection and diagnosis of AD relies on a system that remains focused on the late stage of the disease, despite a better understanding of the disease progression. Clinical practice and healthcare systems' readiness to detect, diagnose and treat the disease effectively are still lagging. The use of biomarkers (cerebrospinal fluid tests (CSF) and positron emission tomography scans (PET)), which are central to a diagnostic assessment for people with AD symptoms, as well as relevant diagnostic facilities are under-utilised. PET imaging is expensive and of limited availability, and CSF sampling may be considered invasive.

The European Brain Council's 'Rethinking Alzheimer's disease: Detection and diagnosis' White Paper has looked at the barriers to early diagnosis and how the healthcare systems infrastructure for detection and diagnosis of AD need to be transformed in order for people with AD to benefit from innovative solutions once they become approved for use. The Rethinking Schizophrenia project falls under the <u>Rethinking the management of brain disorders series</u>, research-driven projects offering policy recommendations to make tangible changes with the aim to improve the lives of people living with brain disorders, neurological and mental alike, across Europe. More details about the outcomes of the Rethinking Alzheimer's disease project can be found in <u>this article</u>.



# V12-003

# Dementia Assessments in Primary Care – Evaluating cognitive testing through a digital platform as part of a standardised procedure

**Miss Wobbie van den Hurk**<sup>1,2</sup>, Dr Maria M. Johansson<sup>1</sup>, Dr Elisabet Classon<sup>1</sup>, Dr Anders Gustavson<sup>3,4</sup>, Prof Katarina Nägga<sup>1</sup>, Dr Anna Segernäs Kvitting<sup>1</sup>

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Diagnosis, diagnostic tools and cognitive assessment

#### **Abstract**

**Aims:** It is highly probable that primary care will play a pivotal role in the initial identification of mild cognitive impairment and dementia. The early symptoms are often subtle and difficult to distinguish from normal aging. Next to reports from the patient and their care partner, a dementia investigation should include standardised symptom questionnaires and objective cognitive tests. However, to deliver such investigations in primary care, there is a need for better tools adapted for the initial evaluation in a primary care patient population.

In this study, we evaluate cognitive testing delivered through self-administration on the digital platform Mindmore, as part of a standardised assessment in primary care.

**Methods:** Study participants were recruited from primary care and consisted of patients who underwent a basal dementia investigation. In addition to their care as usual, they performed a scale for self-reported daily functioning and seven traditional cognitive tests on a touchscreen tablet, supervised by an occupational therapist. Afterwards both patients and occupational therapists shared their experiences through a survey.

**Results (preliminary):** All 51 patients indicated they heard the digital instructor's voice (fairly) well and 94% found the instructions (fairly) easy to understand. Some patients (33%) experienced the tests as difficult, however, the tests were experienced as very stressful by only a few patients (6%). As many as 78% of patients thought they would be able to complete the tests without support.

Occupational therapists stated they intervened during the testing in 55% of cases. In their impression 20% of the patients would certainly, and 21% would maybe, be able to complete the tests without support.

**Conclusion:** Our results show that self-administrated digital cognitive testing is feasible in this primary care patient population. Patient experiences were largely positive; however, professionals highlighted a need for supervision in at least a part of this population.



# V13-001

# Current practice and learning needs of Canadian primary care healthcare providers

Dr Linda Lee<sup>1</sup>, **Mr Michael Lee**<sup>2</sup>, Ms Loretta M Hillier<sup>3</sup>, Dr Carrie McAiney<sup>4</sup>

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

**Aim(s):** To assess the learning needs of primary care providers.

**Method:** 217 primary care providers registered to complete the Multispecialty Interprofessional Team (MINT) Memory Clinic training program, which provides training to establish primary care-based Memory Clinics, were invited to complete a pre-training survey. Using 5-point rating scales (1=Not at all; 5=Extremely), respondents rated their knowledge, skills, and confidence related to dementia care and identified whether they had administered various standardized tools as part of their assessment of memory concerns in previous six months (yes, no, not sure). Respondents were asked to identify their discipline.

**Results:** 72% of registrants (N=157) completed a survey. Respondents included physicians (24%), nurses (27%), and other allied health professionals (49%). Mean ratings reflected that respondents felt they were 'somewhat' knowledgeable about the assessment (3.3; SD=1.0) and management (3.2; SD=0.93) of memory concerns, and 'moderately' able to assess (3.5; SD=1.0) and manage (3.5; SD=0.88) cognitive impairment. Confidence in assessment skills were moderate (3.5; SD=1.0), and was somewhat lower for management (3.3; SD=0.93). Although the majority of respondents had used standardized tools to assess for depression (63%) and cognitive impairment (71%), less than half reported that they had screened for delirium (36%), assessed visuospatial and executive functioning (45%), driving capacity (40%), frailty (24%) or caregiver burden (37%).

**Conclusions:** Limited self-reported knowledge, skills, and confidence related to dementia care and limited use of standardized tools for assessment suggests that there is a significant need for training to build capacity to assess and manage of dementia in primary care.



# V13-002

# **Developing a Training Program based on the Practical Needs of Dementia Care Managers**

Dr Huei-Ling Huang<sup>1,2,3</sup>, Prof Yea-Ing L. Shyu<sup>4</sup>, Mrs Li Yu Tang<sup>5</sup>, Dr Wen-Chuin Hsu<sup>3</sup>

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# **Topic**

**Dementia diagnosis, treatment, care and support:** Education and training for professionals and formal carers

#### **Abstract**

**Aims** This study aimed to explore the training needs and the role functions competencies of dementia care managers, and establish a training model for dementia care managers.

**Method** Qualitative research methods were used. Data were collected with semi-structured, in-depth interviews with dementia care managers (N=33) who work at Integrated Dementia Care Centers and Community-based Dementia Service Stations in north Taiwan. The data were analyzed using content analysis of open-coded interview data after transcribed. And developed this training program based on user needs.

**Results** Participants reported that hoped they could attend the training program to enhance their professional knowledge (such as communication skill, legal of dementia, and palliative care), improve their integration competency to provide care resources to family caregivers, have practical case discussions, and be able to apply it to practice. The training program was based on the results of qualitative interviews, and included a 15-hour Dementia seed care manager training workshop and 40-hour clinical practice for dementia care managers. In this workshop, participants through multiple teaching methods (situational simulation, Team-based learning, case sharing, clinical practicum, and supporting group) to enhance communication, problem solving, resource integration, and dementia care competencies. Moreover, the workshop provided more opportunities for participants to communicate and reciprocate with each other so that participants learned more about partners in the same field and expanded their professional support network. The lecturers of the workshop are experts in the field.

**Conclusion** This training program was developed based on user needs. The results of this study will serve as a reference for the training program of dementia care managers in the future.



# V14-001

# 'Planning Ahead' – A group based approach to Advance Care Planning (ACP) for people living with Dementia and their Carers

Ms Denise Bermingham, Ms Alison Craig, Ms Fiona Killough, Ms Mary McVeigh

Northern Health and Social Care Trust, Antrim, United Kingdom

#### **Topic**

Dementia diagnosis, treatment, care and support: End of life and palliative care

#### **Abstract**

ACP provides the opportunity to communicate future wishes, whilst having capacity - critical within Dementia given cognitive decline. NICE, regional and European guidance recommend ACP conversations occur early following dementia diagnosis, instigated by professionals. In the Northern Health and Social Care Trust the Dementia Navigator service is key in early ACP work. However, research and professionals alike, report avoidance of these conversations, therefore losing the person's voice.

#### **Objectives:**

- 1. Identify best practice in ACP within dementia
- 2. Co-design a model with local service users that empowers people to develop their own ACP
- 3. Increase awareness, reduce stigma and normalise conversations about ACP

**Method:** A Service Improvement and co-design method was used. Existing models/practice and relevant literature were reviewed. Existing ACP resources/templates were collated. Trust Partnership, voluntary sector development and focus groups (service users/carers) co-designed an in-person 2 week programme, 'Planning Ahead'. An evaluation was held of the programme with service users and informal carers.

**Results:** 'Planning Ahead': aimed at those within 3-6 months of dementia diagnosis, with a support person. A supportive interactive structure with information and follow up, comprising of a varied media, professional initiation, family centred strategies, with a focus on ACP for all, not dementia.

**Evaluation:** 9 participants (5 living with dementia, 4 carers) completed 'Planning Ahead' - all recommended the programme. All recorded increase in knowledge of ACP, supports, tools and actual conversations. Social interaction was key, with visual and verbal approaches most effective. A small, non-clinical venue was recommended. A cost effective programme with interest shown in future partnerships. Conversations and planning was continuing at a 6 week review.

**Conclusion:** There is an appetite for a group-based ACP programme for people soon after a dementia diagnosis and their carers. Further pilot of an updated programme is required before production and upscaling of a handbook.



# V15-001

# Oriented Problem Solving Behavior in Nursing Practices in General Hospitals: A Comparison of Hospitals with and Hospitals without Certified Nurses in Dementia Nursing

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Nagano College of Nursing, Komagane, Japan

## **Topic**

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

#### **Abstract**

**Purpose:** This study aims to identify differences in oriented problem solving behaviors in nurses working in general hospitals with certified nurses in dementia nursing (DCN)(Group with DCN) and those without the certified nurses (Group without DCN).

**Method:** We used a questionnaire comprised of items from the Scale of Oriented Problem Solving Behavior in Nursing Practice (OPSN), as well as questions about the length in years working as a nurse, assigned ward, the size of the hospital, and the presence or absence of certified nurses in dementia nursing. This study was conducted with the approval of the Ethics Committee of the Nagano College of Nursing (No.2022-29). We randomly sampled 250 general hospitals from the Japan Hospital Association Directory, distributed 5,000 questionnaires to 20 nurses per hospital through the nursing director of each hospital, and collected 1,509 responses (30.2%). Of these, 1,352 (89.6%) were valid and included in analysis.

**Results:** For the length in years working as a nurse, there was no significant difference between the Group with DCN (n = 650) and the Group without DCN (n = 585). The total score of the Nursing excellence scale in Clinical Practice of the Group with DCN (95.1  $\pm$  115.99) was significantly higher than the Group without DCN (92.53  $\pm$  114.96).

**Conclusion:** Nurses at hospitals with DCN had significantly better skills in solving nursing problems than those at hospitals without DCN, suggesting the influence of the assignment of highly specialized nurses. We need to conduct a more detailed investigation on this issue in the future.



# V16-001

# Remaining and strenghtening hope and couplehood when living with dementia

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Memory Association of Oulu Region, Oulu, Finland

### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### Abstract

Dementia is different for everyone. You know that the dementia progresses, but you don't know how fast and with what type of symptoms. Both the person with dementia and the spouse must face the limitations of life and live in uncertainty, which might be mentally demanding. You would have to be hopeful and gradually give up so much at the same time.

Hope means noticing the good in this moment and in the future. It is also a remarkable factor affecting the quality of life. Close human relationships are one of the most significant factors that strengthen hope. Therefore it is important to support the relationship and provide opportunities for peer support when living with dementia. Genuine encounters, supporting existing resources, having a timely and correct information, and recognizing the meaning of own life are essential for hope.

Hope & Memory project, funded by Finland's Ministry of Social Affairs and Health, organizes versatile activities and shares information that strengthens spouses' hope and help them take care of their couplehood on the journey of dementia. Most of the couples are elderly, but the project also organizes activities for couples with younger onset dementia. About a hundred couples participate in the activities every year.

Professionals' skills to encounter a person with dementia and carer can either strengthen or diminish hope. Dementia field needs more mental health know-how. That's why Memory & Hope project develops and implements a new kind of training model for professionals together with The Finnish Central Association for Mental Health.



# V16-002

# Potential of Early Diagnosis and Post-diagnostic Support Programme to Reduce Old Age Home Admission upon Hospital Discharge in People with Dementia

**Ms Bel Wong**<sup>1</sup>, Dr Kenny Chui<sup>1</sup>, Prof Helen Chan<sup>2</sup>, Miss Tobi Cheng<sup>1</sup>, Ms Florence Ho<sup>1</sup>, Prof Timothy Kwok<sup>1,3</sup>

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#### **Topic**

**Dementia diagnosis, treatment, care and support:** Post diagnostic support for people with dementia and carers

#### **Abstract**

**Aim:** This study aimed to explore factors associating with old age home (OAH) admission upon hospital discharge in people with dementia (PWD).

**Method:** Data from hospital admission episodes of community-dwelling PWD at a convalescent hospital were examined. The outcome measure was OAH admission upon hospital discharge. Demographic and clinical data were collected as potential factors. Independent samples t-test and chi square test were performed to compare the participant characteristics between OAH group and non-OAH group. Univariate logistic regression was performed to identify candidate factors (p<0.2) in the multivariate logistic regression analysis. The data came from the research of a transitional care intervention for PWD developed by Jockey Club Centre for Positive Ageing supported by the funding of The Hong Kong Jockey Club Charities Trust.

**Results:** N=1,054 hospital admission episodes were examined. OAH group had a significantly lower proportion of female participants and fewer participants living with children or maids, while it had a significantly higher proportion of participants with a principal diagnosis of dementia or related disturbances and more participants living alone. Participants in OAH group had significantly longer hospital stay, higher fall risk, and fewer comorbidities. OAH group was comparable with non-OAH group in age, cognitive functioning, while it had better ambulation. Multivariate logistic regression revealed that principal diagnosis of fall, fracture, dementia or related disturbances, living alone, and longer hospital stay were predictors of OAH admission, while living with maid was protective factor.

**Conclusion:** Old age home admission upon hospital discharge in people with dementia was associated with fall, fracture, or dementia-related diagnoses and length of hospital stay. Early diagnosis and post-diagnostic support programme with focuses on preserving cognitive capacity, fall prevention such as supervised physical exercise and osteoporosis screening, and care partner support has a potential to prevent dementia- and fall-related hospital admissions, thereby reducing OAH admission.



### V17-001

# Living Well with Dementia: Therapy tHrough Occupational Role (THOR) programme in NTUC Health Senior Day Care in Singapore

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NTUC Health Co-operative Limited, Singapore, Singapore

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Introduction:** Engaging in meaningful occupations, roles, and routines and staying connected are important in maintaining an individual's physical and functional abilities, and well-being. This is especially crucial for people who value their roles in contributing and caring for others.

**Aim:** The THOR programme aims to engage clients with cognitive impairments in purposeful work-like activities at the centres with consideration of past occupations, life roles, and values; to maintain their cognitive and physical function and boost their self-identity and well-being.

**Method:** We recruited clients who demonstrated a willingness to engage in the programme. Inclusion criteria were

- Modified Barthel Index: Minimal to Mild Dependency (99-75)
- Functional Assessment Staging Tool: Stages 3-5
- Utilising the person-centred approach, work tasks were selected and customised according to the client's abilities, preferences, and life roles and trialled with support from the Dementia Practitioner (DP) and staff.
- Regular reviews by DP and verbal feedback from the clients and staff were collected for adjustment, continuous support, and further improvement.

**Results** We have recruited 44 clients across all senior day care centres.

Some clients shared they felt satisfied because the tasks allowed them to tap into their past roles and contribute to helping others. They were willing to continue in the programme.

**Conclusion** The programme provides a structured process to meet the needs of clients partaking in valued occupational roles and changing the care approach from "doing for" to "doing with". A positive, supportive environment and close collaboration with various stakeholders are vital in ensuring its sustainability.



# V17-002

# Facilitators And Barriers to implementing Cognitive Stimulation Therapy groups for people with dementia in Ireland (FAB CST)

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National College of Ireland, Dublin, Ireland

#### **Topic**

Dementia diagnosis, treatment, care and support: Psychosocial interventions

#### **Abstract**

**Aims:** Cognitive stimulation therapy (CST) is the most highly recommended psychosocial intervention for those living with mild-moderate dementia. Although hundreds of healthcare practitioners are trained to deliver CST, an 'implementation gap' has emerged where CST is not routinely available. This research aimed to examine the facilitators and barriers to the implementation of CST in Ireland.

**Methods:** This mixed methods research included two phases. In phase 1, trained CST practitioners (n= 75) completed a survey assessing level of implementation, acceptability, and perceived efficacy of CST (quantitative, cross-sectional). In phase 2, using a template developed by the International CST Centre and based on the Consolidated Framework for Implementation Research (CFIR), qualitative interviews examined when/where barriers to CST implementation occurred and possible strategies to overcome such barriers. Interviews were conducted with dementia policy professionals (n=5), healthcare professionals (n=6), family care partners (n= 5) and people living with dementia (n=5). Framework analysis is currently underway to analyse the data.

**Results:** Analysis is underway and is due to be completed by December 2023. For phase 1, descriptive statistics will provide an overview of the profile of CST practitioners as well as their level of implementation, acceptability, and perceived efficacy of CST. For phase 2, qualitative thematic framework analysis (completed in MAXQDA) will explore facilitators and barriers to the implementation of CST with our three stakeholder groups.

**Conclusions:** This research will allow us to gain a greater understanding of the implementation and delivery of CST and any potential barriers. Recommendations will be made to inform clinical and policy decisions. The research will also contribute to efforts to increase the availability of evidence-based early interventions for people living with dementia in our communities.



#### V18-001

# A scalable program for improving physical activity in older people with dementia including culturally and linguistically diverse (CALD) groups who receive home support: A feasibility study

**Dr Den-Ching Angel Lee**, Prof Terry Haines, Dr Michele Callisaya, Prof Keith Hill Monash University, Melbourne, Australia

### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Aims:** Older people with dementia/cognitive impairment who receive home care are typically functionally dependent and physical inactive. We pilot-tested a co-designed physical exercise program led by trained community support workers for feasibility, safety, adherence, and potential for benefits on physical activity, physical function, health care use and falls.

**Methods:** Trained community care support workers delivered a 12-week home exercise program to clients with dementia/cognitive impairment, once-weekly for 15 minutes during care shifts, supplemented by carers' supervision of exercises for 30 minutes, three-times-weekly. A physiotherapist provided fortnightly phone support to ensure safety and exercise progression. Participants recorded safety (falls/adverse events) and adherence (exercise days and time) in dairies. Baseline and week 12 assessments using validated scales for physical activity, physical function, daily living independence, falls efficacy, quality of life, self-reported healthcare use, falls and sleep quality were undertaken. Differences were examined with regression analyses.

**Results:** Care support workers (n=26) and client/carer dyads (n=26 and 80.8% culturally and linguistically diverse) participated. Fifteen dyads completed the program. No falls/adverse events occurred with the exercises. Adherence rates against targets for exercise time completed and days exercise was undertaken for support workers were 137%/79.6%, and for client/carer dyads were 82%/104.8% respectively. Physical activity participation, physical function and falls efficacy significantly improved at week 12 compared to baseline.

**Conclusion:** Feasibility, safety and adherence were demonstrated. Strategies to minimise drop-outs in future effectiveness studies are required.



#### V18-002

# Program evaluation and refinement of the "Safe Functional Home Exercise" program for improving physical activity in older people with dementia who receive home care

**Dr Den-Ching Angel Lee**, Dr Michele Callisaya, Prof Terry Haines, Prof Keith Hill Monash University, Melbourne, Australia

#### **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

**Aims:** People with dementia who receive home care have low levels of physical activity participation. This study aimed to evaluate and refine a co-designed physical exercise program for home care clients with dementia, led by trained care support workers.

**Methods:** An action research cycle in which support workers, clients, and carers (each n=26) from the "Safe Functional Home Exercise" feasibility study were invited to complete an evaluation survey. Participants rated statements using Likert-style scales on 1) staff training, 2) staff confidence, 3) program support and 4) satisfaction. Free text space allowed participants to comment about situations affecting exercise performance, improvements for staff training, program support and exercises. The co-design panel (original program designers) reconvened to refine the exercise program based on program outcomes.

**Results:** Support workers (n=19), clients (n=15) and carers (n=13) returned their survey. Support workers (74-90%), carers (77-92%), clients (100%) rated program support positively and were overall satisfied. Support workers (>80%) agreed that the training course was relevant and were confident in delivering the exercises to clients. Situations including "Covid isolation", client's "poor medical condition", and "mood fluctuations" made exercising difficult. Improvements included "making a client video", and "providing tips to motivate clients". The co-design panel modified the exercise program, including adding options for different ways to perform exercises in the "Safe Functional Home Exercise" program for dementia.

**Conclusion:** Future studies are needed to evaluate the refined program in home care.



# V18-003

#### LOVE + ROBOT = LOVOT

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# **Topic**

Dementia diagnosis, treatment, care and support: Rehabilitation

#### **Abstract**

LOVOT was introduced to SingHealth Community Hospitals (SCH) to determine how the social robot can interacts and support patients and staff in community hospital ward. LOVOT was used as an adjunct to regular therapy sessions (either Physiotherapy or Occupational Therapy) and as an interactive companion. The project was carried out over a span of 6 weeks. There were total of 19 participants, of which, 11 were patients (6 were diagnosed with dementia) and 8 staff. 2 questionnaires were administrated for patients and 1 for staff. Short qualitative interviews were also conducted: "If they would like to have LOVOT and reason for their response.

For questionnaire on "Sociability of robot", under Perceived sociability, there were 78% positive feedback, Social influence has 74% positive feedback and Social presence has 70% positive feedback. However, it was noted that some participants (54%) felt that LOVOT was not a real pet during the interaction. For questionnaire on "Older People's Quality of Life (QoL)", administered to patients only, 11 statements had positive agreement. There were 2 statements that had higher disagreement (36%) which were "I look forward to things" and "I try to stay involved with things." It was noticed that 3 out of 11 patient participants gave more than 50% neutral or disagreement to the statements above. Most participants were keen to have LOVOT due to the positive experience, reporting it as an interactive partner and staff felt that it was a good form of stress relief from the hectic work day. Other impacts observed were some patients and caregivers not recruited in the project started to ask about LOVOT and wanted to interact with it as well. Staff looked forward to spending time with LOVOT after a long day of work and were already anticipating for the next LOVOT visit.



# V19-004

# How does loneliness, stress and social isolation manifest in those affected by dementia? Solutions from an Irish dementia landscape.

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The Alzheimer Society of Ireland, Dublin, Ireland

#### **Topic**

**Dementia diagnosis, treatment, care and support:** Social isolation, loneliness, depression and the consequences for people with dementia and carers

#### Abstract

Loneliness is defined as a subjective sense of social isolation. It is internationally recognised as a public health risk, associated with poor health-related consequences and higher rates of mortality. Ireland has the highest rates of loneliness in the European Union.

In May and June 2023, The Alzheimer Society of Ireland surveyed 72 people living with dementia (PLWD) and 597 family carers. Respondents reported on the physical and mental toll dementia exacts on their lives, with references to burnout, stress, concern for the future and a pervasive sense of social isolation. 55% of PLWD said they have felt lonely in the last week, and 30% reported feeling lonely 'a lot' in the last week, with one respondent noting that challenges with communication exacerbate their ability to interact with other people. Family carers also experience higher levels of loneliness, with 21% of respondents stating that they are "never feeling close to other people." Dementia also negatively impacts the mental health of carers; 14% of carers reported feeling depressed 'most of the time,' with 31% rating their mental health as "poor" and 46% noting they felt "worried or anxious in the past week." Many carers reported seeking treatment for mental health issues and suffering a range of stress-related illnesses, including high blood pressure38% of carers reported they struggle to cope with their caring responsibilities, with many expressing concern for the future.

This presentation will share qualitative and quantitative insights on the impact dementia has on the physical and mental health of PLWD and family carers in Ireland as they report on their experiences of loneliness, stress and social isolation. The presentation will centre the lived experience of dementia and highlight key recommendations such as facilitated social interaction, to promote a tangible alleviation to the very real negative outcomes associated with loneliness.



# V20-001

# Nursing skills of visiting nurses supporting home care for dementia patients in Japan: Insights from articles published since 2000

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### **Topic**

Dementia diagnosis, treatment, care and support: Support for people living with dementia

#### **Abstract**

**Purpose** The number of dementia patients receiving home care is increasing, necessitating the enhancement of home care services for these patients. This study aims to uncover the nursing skills of visiting nurses that contribute to the continuity of home care for dementia patients, drawing insights from previous research.

**Methods** Relevant literature was obtained by searching the web version of the Japan Medical Abstracts Society using the keywords "dementia" and "visiting nurse" for original articles published between 2000 and 2022. After filtering, 13 articles met the criteria.

**Results:** Visiting nurses' nursing skills were divided into four categories: "Behavioral and Psychological Symptoms of Dementia (BPSD) management" (6 papers), "Daily living support" (3 papers), "Family support" (3 papers), and "Pain management" (1 paper). BPSD management involved respecting patients' emotions, assess potential risks, and stabilize physical and psychological symptoms. Daily living support included assisting with urination, defecation, and bathing. Family support aimed to improve communication and acceptance within families. Pain management used a pain rating scale for assessment. Visiting nurses primarily focused on BPSD management, with minimal involvement in direct physical care. Home care adjusted the patient-family relationship based on the disease stage to ensure continuous acceptance of the dementia patient.

**Discussion** BPSD management is an essential nursing skill in home care, and visiting nurses approach it professionally to understand patients and improve their lives. In family support, to the focus is on enhancing support by providing knowledge and coping methods related to dementia and improving the Quality of Life (QOL) of the family members.



# **Evaluating Impact of Mindful Immersive Nature Therapy (MINT) Pilot Among Long Term Care Dementia Residents**

**Ms Diana Wei Ling Goh**<sup>1</sup>, Ms Sarah Shu Yi Tang<sup>1</sup>, Ms Zi Gi Cheong<sup>1</sup>, Mr Nicholas Zhan Yuen Wong<sup>1</sup>, Ms Mee Choo Soh<sup>1</sup>, Dr Donald Yeo<sup>2</sup>

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#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

Rich activities empower and enable Persons with Dementia (PWDs) to live inspiring, quality lives. The development of mindfulness, nature therapy and other non-pharmacological interventions is an exciting and growing interest in dementia care. The current study seeks to evaluate the pilot of a nature therapy programme called Mindful Immersive Nature Therapy (MINT) conducted in 2022 and 2023 for 10 dementia residents in long term residential care. A Mixed methods approach was used to investigate if MINT improved the wellbeing of the participants, and what factors were important for maximising its beneficial impact. Pairwise comparisons indicated that the wellbeing scores for the MINT programme were significantly higher than other home routine activities. To further outline the range of impact of MINT, and identify factors important for maximising its beneficial impact, thematic analyses of a focus group discussion with eight staff were conducted. Four positive and two negative themes emerged regarding the impact of MINT on wellbeing. Themes related to the implementation of MINT revealed three enhancing factors and one detracting factor which affected the benefits for the participants, Together, the results indicate that MINT engagement is diverse, dynamic and improves well-being in different domains, and that nature can be a accessible platform for PWDs to engage in mindfulness.



# Improving Long Term Care Dementia Residents' Dining Experience: Evaluating Impact of 'Joy-in-Dining' Activity

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Apex Harmony Lodge, Singapore, Singapore

#### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

Persons with Dementia (PWDs) often experience a decline in the quality of their dining experiences, due to a decreased ability to engage with food and others, resulting in weight loss and nutrient deficiency and compromising PWDs' physical health. This pilot study aims to improve dining experience of PWDs in a long-term care setting through empowerment, social, and physical environmental modifications.

Twenty-one persons with mild to moderate Dementia (M=11, F=10), aged 52-94, each participated in a weekly dining activity named 'Joy-in-Dining' for at least 3 months. Each session involves having dinner in an outdoor garden with environmental stimulation, such as music and scented plants. Engagement was measured using the Engagement of a Person with Dementia Scale (EPWDS) for PWDs across 3 types of dining experiences: Dining as usual (control), garden dining, and garden dining with children. Weight data was collected as a measurement of physical well-being.

A Kruskal-Wallis test showed a significant effect of dining type on how engaged PWDs are during dining ( $\chi 2(2)=8.66$ , p<0.05). Post-hoc pairwise comparisons showed that both garden dining, and garden dining with children, significantly improved EPWDS compared to controls (p<0.05). However, no significant difference was found between garden dining and garden dining with children. Weight data showed high rates (82.35%) of weight maintenance (including non-clinically relevant weight loss of less than 5%) and/or increase.

In conclusion, dining with environmental stimulation promotes engagement in PWDs. However, interaction with children did not appear to further increase engagement. Environmental interventions in dining show promise for weight maintenance in PWDs.



# Comparison Between Effects of Supporting Patients with Alzheimer's Disease Versus Other Chronic Conditions

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# **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Background:** Patient care for Alzheimer's disease (AD) is often provided by informal care partners. This targeted literature review assessed the difference in the impact care partners of people with AD experience compared with other chronic conditions.

**Method:** Search strings identified 1) care partner impact in AD and 2) care partner impact in other chronic conditions. Studies published January 2012-October 2022 were included. Care partner impact was compared using weighted mean values (MV) of questionnaires including the Zarit Burden Interview (ZBI). ZBI is stratified into categories of caregiving impact: Little or none (0 to 21), mild to moderate (22 to 40), moderate to severe (41 to 60) and severe (61 to 88).

**Results:** ZBI was the most frequently used questionnaire; 13 studies reported data in AD and 39 studies reported on 20 other chronic conditions. The impact score ranged from 18 to 48 in AD and the MV was 36, based on 1,703 participants. Burden in other chronic conditions ranged from 5 (chronic musculoskeletal pain) to 59 (bipolar disorder). AD impact on care partners (MV: 36, range: 18-48) was greater than heart failure (MV: 27, range: 16-29) and type 2 diabetes (MV: 26, range: Not reported) but lower than schizophrenia (MV: 56, range: 52-65) and bipolar disorder (MV: 59, range: Not reported).

**Conclusion:** AD has a significant impact on care partners. The value of interventions targeting AD for care partners should be considered in addition to the impact of AD on patients.



# An exploratory investigation of ikigai and living well with dementia in the Japanese Canadian community.

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### **Topic**

Dementia diagnosis, treatment, care and support: Well being and quality of life

#### **Abstract**

**Aims:** A capabilities approach to dementia focuses on how people live well with dementia within their sociocultural contexts. However, there is limited research examining how culture intersects with lived experiences of dementia. Thus, we aim to explore how Japanese Canadians live well with dementia. Furthermore, we examine how *ikigai*, a Japanese wellbeing construct, can enable people to live well with dementia.

**Method:** We took a relational approach and recruited 4 dyads consisting of people living with dementia and their care partners from the Japanese Canadian community. First, we conducted in-depth narrative interviews with the dyads on their experiences of living well with dementia. Next, we gathered in a group art-making workshop to enable participants to identify and articulate what they wanted others to know about how they live well with dementia. Both English and Japanese were used throughout the study so individuals could meaningfully participate in their preferred language. For our preliminary analysis, we analyzed audio recordings of the interviews through narrative inquiry and applied our understandings of *ikigai* as a conceptual lens.

**Results and Implications:** We share preliminary findings from our narrative interviews with Japanese Canadians concerning how *ikigai* can enable live well with dementia. Furthermore, we demonstrate how qualitative methods can promote safe and meaningful participation of people living with dementia and their care partners from culturally diverse populations. This research contributes culturally nuanced knowledge of living well with dementia and informs ways to recognize the agency of people living with dementia and their care partners.



### V22-001

# Point-Example-Elaborate-Link (PEEL) technique for insights translation

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#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

As seniors are non-homogeneous and lived experiences are different, one must acquire an understanding of the human conditions to innovate. New empathy mapping methods and tools to articulate a good understanding of evidence and insights are needed, and better design support for staff who work together with residents to codesign in the community is also needed. Through this study, we (re) introduced the term insights translation for innovation by design involving working professionals to partake in a process of seeking value clarification and describe ideas clearly when codesigning for seniors. A focus group discussion was designed to support employees of an agency in codesigning for dementia, ageing and community health. As design innovation is dependent on its context, participants need to know and demonstrate ways of presenting their ideas well after identifying key personas and completing their journey mapping. We developed a Point-Example-Elaborate-Link (PEEL) technique to help them to present purposively through insights translation. Through comparing three design reviews conducted across similar programmes with same topic of interests, we noticed that direct stakeholders' involvement contributed to the process where value is cocreated with more focus on the emotional aspect. Findings by evidence synthesis and data triangulation also showed that outcomes differed by programme duration and participant type in the practical and social aspects. More can be done to develop/enhance techniques that consider design support for adult participants to ideate outside the box and outside of their comfort zone, by factoring practical, social and emotional dimensions and determinants in design.



# V22-002

# "Enter A New World of Experiences" - An Immersive Room Experience for Persons Living with Dementia in NTUC Health Senior Day Care in Singapore

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### **Topic**

Dementia research and innovation: Assistive technology, Al and innovation

#### **Abstract**

**Introduction** Virtual reality (VR) promotes multisensory stimulation, alertness, pleasure, a sense of control, and social interaction and aids relaxation in persons living with dementia (PLwD).

Harnessing VR, an immersive room experience (IRE) consists of a multisensorial interactive wall and space installation incorporating sights and sounds. The IRE is set on interchangeable

**Background:** panoramic views of Singapore's past and present iconic landmarks and VR games for PLwD.

**Aim** We aim to examine the benefits, receptiveness, and feasibility of IRE for PLwD in the day care settings, whereby some clients have difficulties accessing the various landmarks physically.

**Method** A total of 122 PLwD (mild to moderate severity) was selected for the IRE across 3 centres. The PLwD were engaged in videos and virtual games for 30-minute group sessions led by trained staff using the facilitation guide.

The Engagement of a Person with Dementia Scale (EPWDS) and a post-session survey were administered from March 2023 to June 2023.

**Results** Over 80% of PLwD achieved a score of more than 4 out of 5 for engagement in positive domains (affective, visual, verbal, behavioral, and social aspects) in EPWDS. Seventy-four responses were gathered through the Post Session Survey. Results showed that 82.5% and 77% of PLwD enjoyed the videos and games respectively. The majority would be keen to participate in IRE again.

**Conclusion** The PLwD were generally receptive to IRE as they reminisced fondly about videos from the past and appreciated the new architectural sites like Jewel Changi which provided a fresh perspective on reality.



# V22-004

# Assistive Technology Uses in Community-Based Dementia Care Center

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#### **Topic**

**Dementia research and innovation:** Assistive technology, Al and innovation

#### **Abstract**

**Background:** With the development of science and technology, explore whether using mobile application (App) in the community-based dementia care center bring benefits to the people with dementia and their family members.

**Method:** The research provides a digital care Note App in the community-based dementia care center, using a qualitative method. In this study, 4 people with dementia and 4 people are their family members are selected for analysis with a semi-structured questionnaire interview.

The results of this research are as follows:

The use of the digital care Note App in the community-based dementia center is beneficial: In the community-based dementia care center, the social workers assist the people with dementia to measure and record blood pressure, pulse and other values on the App before the activity. When the data exceeds the individual's average reasonable range, the communication software connected to the App will send urgent notifications to inform their family members, enabling them to monitor the condition of the dementia. Additionally, this App has a digital contact book letting the family members know about the performance of people with dementia in the activity. Through the information of a digital contact book, their family members can give appropriate feedback to the people with dementia and establish a good family support system.

The dilemma of promotion and use in the family members: The research found it was obvious difficulties to teach the family members how to use the App and connect to the communication software through the videos. However, by the practical guiding the family members greatly improves their willingness to use this App in the future.



# V23-001

# Time to progression through AD stages and associated probability of long-term care

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#### **Topic**

Dementia research and innovation: Epidemiology

#### **Abstract**

**Introduction:** Alzheimer's disease (AD) progresses along a continuum often categorized into discrete stages: preclinical, where no symptoms are apparent, followed by mild cognitive impairment (MCI) and eventually dementia that progresses from mild, through moderate to severe.

**Objectives:** To describe progression across stages of AD, including death, and to estimate the probability of long-term care (i.e. institutionalization) with AD progression.

**Methods:** The National Alzheimer's Coordinating Center collects annual follow-up data from participants with unimpaired cognition, clinically diagnosed MCI-AD or dementia due to AD seen at participating National Institute of Aging-funded AD Research Centers. AD stages were defined by the CDR global score, and annual transitioning probabilities among participants were modelled using multistate Markov models.

**Results:** The study included participants with unimpaired cognition (13,692 [48.5%]); MCI-AD (7,075 [25.1%]); and AD dementia (7,453 [26.4%]). The annual transitioning probabilities to more severe stages were 0.251, 0.333, and 0.311 among participants with MCI-AD, mild AD dementia, and moderate AD dementia. The annual probabilities of death were 0.005, 0.007, 0.008, 0.053, and 0.253 among unimpaired cognition, MCI-AD, mild, moderate and severe AD dementia, respectively. Among participants without long-term care, MCI-AD participants had eight times higher, mild AD dementia participants had 27 times higher, and moderate and severe AD dementia participants had 56 times higher annual probabilities of long-term care than cognitively unimpaired participants.

**Conclusion:** Understanding the progression of AD and associated risk of long-term care are important for characterizing the impact of AD across its continuum and the potential value of disease-modifying therapies.



# V24-001

# Design and implementation of a Massive Open Online Course on care for people with dementia - an international, culturally sensitive approach

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#### **Topic**

Dementia research and innovation: International collaborations, challenges and opportunities

#### **Abstract**

The needs-based care of people with dementia is of high importance, both in industrialized and in low- and middle-income countries. Especially low and middle income countries are facing particular challenges, which are mainly related to the insufficient financial as well as structural conditions in order to adequately address these challenges and to develop appropriate solutions, it is essential to build up a wide range of knowledge.

Within the framework of a project funded by the German Academic Exchange Service (DAAD), a 10-module Massive Open Online Course was jointly developed an designed. The MOOC covers culture- and country-specific aspects as well as the types of dementia and related typical symptoms and behaviors and numerous non-pharmacological therapies and interventions. Ethical issues, research methods and the use of low tech technical assistance devices were also addressed. The course is accompanied by 12 weekly online meetings in which German and Dominican students of medicine, physiotherapy, nutrition and health sciences exchange information and work together in international small groups on the content.

The course is currently in its 5th cycle and more than 150 students have successfully completed the course. The course has been included in the standard curriculum at both the Dominican and German participating universities. Furthermore, within the framework of the scientific monitoring, it could be demonstrated that ¾ of the participants were able to record a significant increase in knowledge about the care of people with dementia. In addition, 30 German and Dominican students were able to participate in a 10-day exchange program and visit various health care facilities in both countries.



# V25-001

# Generating priorities for future dementia and hearing research: A James Lind Alliance Priority Setting Partnership

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#### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

**Introduction:** Dementia and hearing conditions are important public health concerns and often coexist. Acquired hearing is the largest potentially modifiable risk factor for the subsequent development of dementia. Little is known about the needs and priorities of individuals experiencing both dementia and hearing conditions together, despite evidence of their individual impacts.

People who live with dementia and hearing conditions, along with their caregivers, have been identified as underserved groups who are often under-represented in research, and they may belong to additional underserved groups (e.g., ethnic minority groups). Underserved groups must be supported to participate to ensure findings are representative.

Given policymakers require patient-focused evidence to guide decision-making, we must enable those who would benefit from research to voice what matters to them. A James Lind Alliance (JLA) Priority Setting Partnership (PSP) has therefore been launched with the aim of partnering with patients, carers and clinicians to identify priorities for research about the prevention, diagnosis and treatment of coexisting dementia and hearing conditions.

**Methods:** The JLA PSP method entails the following key stages: 1. Steering group formation; 2. First survey to collect initial priorities; 3. Collating priorities and examining the literature to see if the priorities are unanswered by research; 4. Second survey for interim priority setting; 5. Final workshop to achieve consensus on the top 10 priorities; 6. Dissemination. Throughout evidence-based strategies for inclusivity will be incorporated.

**Results:** The diverse steering group has been formed, including people with lived experience of dementia and hearing conditions, carers, clinicians and user organisation representatives from the Royal National Institute for Deaf People, Alzheimer's Research UK and Alzheimer's Society. The project is ongoing, with priority collection currently underway.

**Conclusion:** Produced will be a prioritised agenda for research about dementia and hearing conditions shaped by the people its outcomes will directly impact, guiding funders, commissioners, investigators, campaigners, and policymakers.



# V25-002

# NEW APPROACH AND FUTURE TREATMENTS TO REDUCE DEMENTIA RISKS

#### Ms Luiza Cardoso Cajazeira

Uniasselvi, Salvador, Brazil

#### **Topic**

**Dementia research and innovation:** New and future approaches and treatments

#### **Abstract**

The desire to contribute to this topic was driven by direct and personal contact with this illness present in my own family (my mom, aged 95), added to my appreciation, skill and confidence in the applicability of Research as a tool of great scientific value. I experience the complexity of this multifaceted disease up close, which requires the development of effective measures, capable of minimizing the impacts on the health of the sufferer, reducing risks and related problems. This is a disease that affects not only the patient, but their entire social group, since the family, in most cases, is not prepared or has sufficient knowledge to safely deal with the situation, and end up limiting themselves to palliative treatments. This project goals are:

Disseminate and expand Research into the action of a specific NATURAL SUPPLEMENT formula, already being tested, prepared with the participation of Technicians and Specialist Pharmacists, aiming to test and prove its effectiveness on alarger scale;

Raise awareness among family members and interested parties about prevention and forms of natural and complementary intervention for the rehabilitation of damage to the neural system in patients with Dementia or Alzheimer's;

Stimulate and develop trainings for Caregivers with simple neuropsychological stimulation activities;

Guide the use of Integrative and Complementary Medicine as part of complementary and integrative medical intervention in the health of patients with the disease;

The 5 pillars of this Method are:

Individualized ASSESSMENT/Anamnesis;

- FOCUS on promoting health as a whole, and not just on intervening and treating the disease Integrative and Complementary Medicine associated with Conventional Treatment;
- POSITIVE VITALITY Physical activities and cognitive stimulation;
- ENVIRONMENT Training of Caregivers and Family Members 5
- DATABASE basis and source for conclusions about research results, improvement and feedback.

For more details and information, please head to: <a href="https://drive.google.com/file/d/1NvXJKogZFmtyC4N32samDCROxee4tGkk/view?usp=sharing">https://drive.google.com/file/d/1NvXJKogZFmtyC4N32samDCROxee4tGkk/view?usp=sharing</a>



# **V26-001**

# Nonpharmacological Tactile Activity Interventions for Reducing Behavioural and Psychological Symptoms of Dementia in the Acute Hospital Setting: An Integrative Review

**Ms Erin Rachel Davis**, Dr Christina Aggar, Dr Michelle Bissett Southern Cross University, Gold Coast, Australia

### **Topic**

Dementia research and innovation: Non-pharmacological interventions

#### **Abstract**

Accepted for publication in the Journal of Clinical Nursing on the 13th September 2023.

**Aim:** To review existing research on nonpharmacological tactile activity interventions for reducing behavioural and psychological symptoms of dementia in the acute hospital setting.

**Background:** When people living with dementia are hospitalised, they often experience an exacerbation of behavioural and psychological symptoms of dementia. Pharmacological interventions are commonly used to manage behavioural and psychological symptoms of dementia despite the low success rate and the heightened risk of morbidity and mortality. Low-cost alternatives that are implementable at the bedside are nonpharmacological interventions such as tactile activity interventions.

**Methods:** Four databases were searched using the PRISMA framework to guide the search and screening. Eligible studies were evaluated using the Mixed Method Appraisal Tool and analysed using Thematic Analysis. The PRISMA checklist was used to evaluate the current study.

**Results:** Seven studies described tactile activity interventions for behavioural and psychological symptoms of dementia in acute hospital settings, commonly as an element of multicomponent sensory interventions. Two themes emerged as key to implementation: human resources and the right intervention for the right person.

**Conclusion:** There is limited evidence exploring tactile activity interventions for reducing behavioural and psychological symptoms of dementia in acute hospital settings. Individualised approaches, in combination with staffing expertise, appear central to implementation.

**Relevance to Clinical Practice:** Acute hospital settings can result in increased behavioural and psychological symptoms of dementia, which can be distressing for patients and families and challenging for nursing staff. Tactile activity interventions may offer a low-resource bedside option to support people with dementia in acute health settings.



### **V26-002**

# A Sense of Familiarity: Dementia Design in Nursing Homes - a scoping review protocol

Dr Joanna Sun<sup>1,2</sup>, Dr Sumiyo Brennan<sup>3</sup>, Prof Therese Doan<sup>4</sup>, Ms Anne Fahsold5

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#### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

#### **Abstract**

The number of older adults living with dementia is growing exponentially due to increasing life expectancy, medical advances in physiological health and lifestyle factors increasing one's risk of dementia. With a growing ageing population living with dementia globally, a portion of the population will require high levels of continuous nursing care throughout the day due to complex medical needs, safety concerns, or the lack of caregiver support. However, in many countries, there may not be additional services that can enable people living with dementia with higher care needs to age in place within the community. Therefore, nursing homes have a significant societal role, offering professional medical care and a safe and secure environment. However, these environments are feared and stigmatized despite the significant benefits that nursing homes can provide. Nursing homes are commonly seen as institutional pathogenic environments that are undignified, disconnected and isolating. Dementia design recommendations, however, seek to address this by promoting environments familiar to people living with dementia in nursing homes. Familiar environments are associated with salutogenesis, improved well-being and increased quality of life. This scoping review seeks to uncover the underpinning characteristics or elements associated with "familiarity" in the nursing home environment that provides care for people living with dementia.



# **V26-003**

# Co-designing a nature-based pilot research project with people living with dementia and care partners: Lessons learned

**Dr Constance Dupuis**<sup>1,2</sup>, Dr Anthea Innes<sup>1</sup>, Ms Equity Burke<sup>1</sup>, Ms Mason McLeod<sup>1</sup>, Ms Maria Belen Miguel<sup>1</sup>, Ms Rachel Raj<sup>3</sup>

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#### **Topic**

**Dementia research and innovation:** Non-pharmacological interventions

#### **Abstract**

**Aims:** This paper discusses the process and outcomes of a co-design project with people living with dementia and their care partners, leading to the development of a nature-based social health and wellbeing pilot project. This paper contributes to the growing recognition of the importance of participatory approaches in dementia research.

**Methods:** The co-design process, involving people living with dementia (n=2), care partners (n=2), and a former care partner (n=1), consisted of collaborative sessions to identify the needs, preferences, and aspirations of the participants. Iterative feedback loops facilitated the development of a project tailored to the requirements and desires of the target group. Practical exercises, such as visiting potential project locations, demonstrate the importance of abstract and practical engagements in the co-design of research.

**Results:** Several key priorities emerged, including the importance of connections to nature and the outdoors, social connections, and accessibility. Insights and learnings were gained for future co-design work with people living with dementia, including tools for group priority setting and ways to ensure participation and understanding.

**Conclusion:** The co-design process underscored the value of involving individuals with lived experience in the development and evaluation of interventions for dementia care. The insights gained contribute to the growing body of knowledge on participatory approaches in dementia care. The findings highlight the importance for people living with dementia and for the research design of incorporating the perspectives of individuals living with dementia and their care partners, promoting person-centered and holistic care practices.



# V27-001

# A human rights-based framework for qualitative dementia research

#### Ms Alicia Diaz-Gil

Oxford Brookes University, Oxford, United Kingdom. Oxford University Hospitals NHS Trust, Oxford, United Kingdom

### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

## **Abstract**

**Background and Objectives:** People living with dementia have historically been excluded from qualitative research and their voices ignored due to the perception that a person with dementia is not able to express their opinions, preferences and feelings. Research institutions and organizations have contributed by adopting a paternalistic posture of overprotection. Furthermore, traditional research methods have proven to be exclusionary towards this group. The objective of this research is to address the issue of inclusion of people with dementia in research and provide an evidence-based framework for dementia researchers based on the five principles of human rights: Participation, Accountability, Non-discrimination and equality, Empowerment and Legality (PANEL).

**Design:** This research adapts the PANEL principles to the research context, and uses evidence from the literature to create a framework for qualitative research in people with dementia. This new framework aims to guide dementia researchers in designing studies around the needs of people with dementia, to improve involvement and participation, facilitate research development and maximize research outcomes.

**Results:** A checklist is presented with questions related to the five PANEL principles. These questions cover ethical, methodological and legal issues that researchers may need to consider while developing qualitative research for people with dementia.

**Conclusions:** The proposed checklist offers a series of questions and considerations to facilitate the development of qualitative research in patients with dementia. It is inspired by current human rights work of recognized dementia researchers and organizations who have been directly involved in policy development. Future studies need to explore its utility in improving participation, facilitating ethics approvals and ensuring that outcomes are relevant to people with dementia.



### V27-002

# Increasing our knowledge within brain imaging of neurodegenerative disorders across diverse populations

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#### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

#### **Abstract**

The underrepresentation of ethnic diversity in research, especially within imaging focused on neurodegenerative disorders, such as Alzheimer's disease (AD) is a significant concern. This lack of diversity has resulted in a knowledge gap where the majority of our insights are primarily derived from white/European populations within North America/Europe, which may not be generalizable. We began the UNITED Consortium (Uncovering Neurodegenerative Insights Through Ethnic Diversity) with the overarching goal of enhancing diversity and consequently enriching the global understanding of neurodegenerative diseases. Our mission extends to establishing a global platform for researchers and clinicians to advance research efforts and provide research support to those in need. The consortium now includes over 125,000 individuals representing 84 global locations, supported by an online platform that streamlines data processing and analysis.

In addition to this we are exploring other potential avenues to overcome barriers within global representation in this field. One barrier is the limited access to brain imaging facilities within many countries due to high costs, and lack of infrastructure. Globally, access to magnetic resonance imaging (MRI) varies widely, with low-income countries average at 0.18 MRI scanners per 1 million population, and high-income at 26.52. Recent developments within more affordable and accessible imaging methods, such as artificial intelligence methods and ultra-low-field MRI, are extremely promising. In collaboration with a multidisciplinary team within the Netherlands, Paraguay and Bolivia we are currently exploring the performance of ultra-low-field MRI technology in communities where a conventional MRI setup is not feasible. The technology has the potential to revolutionize the landscape of dementia research and care due to its portable, affordable and easy-to-use design. Through this initiative, and other ventures, the UNITED Consortium aims to empower international researchers and increase the representation and knowledge base encompassing diverse global populations within imaging of neurodegeneration.



# **V27-003**

# Improving the inclusion of under-served groups in research about co-existing dementia and hearing loss: An experience-based co-design study.

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### **Topic**

**Dementia research and innovation:** Underrepresented populations and dementia: increasing inclusivity, diversity, and access

#### **Abstract**

**Aims:** Many people living with dementia also live with hearing loss. Furthermore, hearing loss is a key risk factor for dementia. It is vital that research into these conditions includes under-served groups (e.g., ethnic minorities, LGBTQ+ community, sign language users) to address health disparities and support generalisability. This study aimed to identify barriers to research participation for these groups. This represents the first phase of a co-design project to improve the engagement of under-served groups in dementia and hearing research.

**Method:** To identify research participation barriers, individual and group interviews were conducted with (1) twenty-four experts by profession (e.g., researchers, clinicians, social workers) and (2) twenty-five experts by experience (e.g., people living with dementia and/or hearing loss, family carers). They then ranked these barriers at a joint meeting. Purposeful sampling was used to recruit participants from various under-served communities. The data were analysed using reflexive thematic analysis.

**Results:** Common barriers to research participation included limited digital/health literacy, stigmatisation of dementia and/or hearing loss, mistrust in healthcare/research organisations, and inaccessible information about dementia and hearing loss. Additionally, research culture and norms can inhibit inclusivity (e.g., inflexible working times/locations, reliance on healthcare services for recruitment). Poor communication with healthcare services and participants (e.g., jargon, cultural insensitivity) and a lack of empathy for participants were particularly problematic. Finally, potential participants must often battle to access healthcare, which limits their capacity to engage in research.

**Conclusions:** This study has uncovered key barriers to participation in dementia and hearing research for under-served groups. The findings have important implications for researchers, clinicians, funders, universities, healthcare services, and charities. The next stage of this research entails partnering with experts by experience and by profession to co-design strategies and resources to improve the inclusion of under-served communities in this field of research.



## V28-001

Awareness creations on choline nutrient prolonged dietary deficiencies, Millard's reaction products from over processed foods and persistent oxidants-antioxidants imbalance as known risks factors for the development of frank Alzheimer's disease in the adult years: how to protect and reduce vulnerability to these risks factors

#### Mr Vincent Oghenekevbe Olughor

Faculty of Pharmacy, Department of Pharmaceutics and Industrial Pharmacy, University of Ibadan, Ibadna, Nigeria

#### **Topic**

Dementia risk reduction: Dementia and nutrition

#### **Abstract**

**Aims:** To create global awareness on risks factors of Alzheimer's disease which include: prolonged dietary nutrient deficiency, Millard's reaction products and prolonged oxidative stress from oxidants-antioxidants imbalance.

**Method:** From threaded literature reviews' data and analyses.

**Results:** Levels of acetylcholine are particularly low in the brains of people with Alzheimer's disease. Overtime, different areas of the brain shrink;

Acetylcholine is the neurotransmitter at neuromuscular junctions, at synapses in the ganglia of the visceral motor system, and at a variety of sites within the central nervous system;

Prolonged dietary deficiencies of choline, persistent exposures to Millard's reaction products from foods that are over processed by dry heat of greater 126 C as well as prolonged oxidative stress from oxidants-antioxidants imbalance are known risks factors for the development of frank Alzheimer's disease during adult years. The symptoms of frank Alzheimer's disease persist for at least 5 years and lead to death of the affected person's;

Choline dietary supplement is required to augment the quantity produced by the body, and choline is required by the body in sufficient quantity daily to produce the neurotransmitter, acetylcholine and S-adenosyl-methionine (SAM), a universal methyl donor;

SAM is an important molecule in normal cell function and survival. SAM is utilized by three key metabolic pathways: transmethylation, transsulfuration and polyamine synthesis;

Deficiency of dietary choline is observed worldwide, with approximately 90% of Americans being deficient. Previous work highlights a relationship between decreased choline intake and an increased risk for cognitive decline and frank Alzheimer's disease;

The prevalences of Millard's reaction products and prolonged oxidative stresses are also worldwide;

Inflammation and the pathological progression of Alzheimer's disease are associated with: low circulating choline levels, presence of oxidative stress and Millard's reaction products.

Conclusion: More awareness will be created at the Conference.



### V29-001

# The relationship between different patterns of physical activity and cognitive function in older adults

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## **Topic**

Dementia risk reduction: Dementia and sport

#### **Abstract**

**Aims:** Physical activity (PA) may be an accessible way to protect cognitive function, but which PA patterns take effect is unclear. We sought to explore the association between PA patterns and cognitive function in specific groups.

**Methods:** This cross-sectional study used the data from the 2018 survey of China Health and Retirement Longitudinal Study. Cognitive function was assessed by Mini-Mental State Examination. Multivariable linear models were conducted to examine the associations of self-reported frequency and duration in different PA intensities with cognitive function. Subgroup analyses were performed by age and sex.

**Results:** A total of 5402 respondents aged  $\geq$ 60 were included. Compared with no PA, 4-7 days/week on moderate PA (MPA) ( $\beta$ =0.31, 95% CI: 0.09, 0.53) and light PA (LPA) ( $\beta$ =0.32, 95% CI: 0.04, 0.60) showed better global cognition, while it reversed on vigorous PA (VPA) ( $\beta$ =-0.51, 95% CI: -0.77, -0.25). With <0.5 hours/each time as reference, 0.5-4 hours/each time on MPA and LPA showed better global cognition, while  $\geq$ 4 hours/each time on VPA ( $\beta$ =-0.63, 95% CI: -0.94, -0.33) and LPA ( $\beta$ =-0.43, 95% CI: -0.79, -0.07) showed worse global cognition. Similar results were found in most cognitive domains and respondents aged 60-75. Compared with men, trends above were more pronounced among women.

**Conclusions:** Excessive PA is negatively associated with cognitive function. Only with more frequency, appropriate duration and intensity, there is a positive associated with better cognitive performance.



# SENSE-Cog Lewy: Investigating sensory loss in people with dementia with Lewy bodies (DLB): a scoping review

**Ms Rachel Louise Fitzpatrick**<sup>1</sup>, Ms Sin Chai<sup>1</sup>, Dr Adam Roche<sup>1</sup>, Dr Panos Alexopoulos<sup>2</sup>, Prof Iracema Leroi<sup>1,3</sup>

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aim:** To shed light on current evidence on the frequency of sensory loss in individuals with dementia with Lewy bodies (DLB), and the relationship between sensory loss and cognitive/non-cognitive symptoms of DLB.

**Methods:** A scoping review was undertaken using Embase, CINAHL, PsychINFO and PubMed. Only reports on people with DLB (from any stage, prodromal to late stage) were considered. Papers primarily addressing other forms of neurocognitive disorders were excluded. Sensory loss was conceptualized as the loss of vision, hearing, or smell resulting from physical causes, such as cataracts. Two reviewers independently assessed each study for inclusion, and disagreements were resolved by a third reviewer.

**Results:** Reports on sensory loss in DLB were very few and most often were comparing sensory loss across different dementia types. Strong associations were observed between sensory loss and the severity of both cognitive and non-cognitive DLB symptoms. Visual hallucinations, for example, were found to be closely linked to visual loss.

**Conclusions:** This review highlights a significant gap in research regarding the frequency of sensory loss in DLB and the relationship between sensory loss and cognitive/non-cognitive DLB symptoms. Furthermore, it highlights the importance of conducting such research, given the hints on the association between sensory loss and DLB symptoms and the well-established relationship between sensory loss and symptoms of other forms of neurodegenerative diseases, particularly Alzheimer's disease.



# Memory trajectories and the potential mechanisms in older people: A longitudinal cohort study

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** To explore the trajectories of memory changes in older people, identify the modifiable influencing factors of memory trajectories, and examine the longitudinal causal mediation relations among the factors and memory.

**Methods:** We included 5665 older adults from a cohort study. Data about memory performance, self-reported sleep duration, moderate-to-high intensity physical activity levels, depressive symptoms were analyzed. We used group-based trajectory modeling to identify the latent memory trajectories, applying multinominal logistic regression to figure out the predictors of memory trajectories, adopting restricted cubic splines to identify the non-linear relations between variables, performing longitudinal mediation analysis to reveal the potential causal mechanisms.

**Results:** Three trajectories of longitudinal memory changes were identified: stable trajectory (27.0%), slow decline trajectory (54.1%), and fast decline trajectory (18.9%). Sleep duration, physical activity levels and depressive symptoms were significant predictors of memory trajectories. The optimal sleep duration for memory performance was around 6.5 hours for most individuals. Subtle differences existed among individuals with different ages or levels of education. The optimal physical activity volume for memory performance was about 55 MET-hours per week (around 1.75-hour moderate physical activities per day), and it dropped to 35 MET-hours (around 1.11-hour moderate physical activities per day) for individuals who attended middle school and beyond. Longitudinal mediation analyses indicated that shorter sleep duration could negatively affect memory performance directly or indirectly via increasing depressive symptoms.

**Discussion:** Older adults followed three different trajectories of memory changes, which could be predicted by sleep duration, physical activity levels, and depressive mood. Inadequate sleep duration may cause memory decline directly or indirectly via depressive mood. Keeping the optimal sleep duration and physical activity levels tends to exert the greatest benefits.



# Effects of psychosocial factors in patients with subjective cognitive decline, mild cognitive impairment, and Alzheimer's disease

#### Miss Weijia Xu

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#### **Topic**

Dementia risk reduction: Risk factors

#### **Abstract**

**Aims:** Social support and mental health are important psychosocial factors for older adults' health. Thus, we examined the associations of social support, mental health, and cognitive function in people aged 45 years and above.

**Methods:** A total of 219 individuals aged 45 and older from China were obtained, and divided into three cognitive groups. The MCI and SCD group practised Baduanjin exercise for 14 weeks, with the frequency of 30 min a day and 5 days a week. The AD group received fitness walking training. All 3 groups were provided with a 60-minute health education session, psycho-behavioral program and cognitive training, once every 2 weeks for 14 weeks. Neuropsychological assessment, the Subjective Cognitive Decline Questionnaire (SCD-Q21), the Social Support Rating Scale (SSRS), and the Adult Mental Health Scale (AMHS) were used for data collection and analysis.

**Results:** Age and education level had statistically significant differences in the scores of MoCA and MMSE (p < 0.01). There were significant differences in MoCA (p < 0.001), MMSE (p < 0.001), SCD-Q21 (p = 0.001), and AMHS (p = 0.008) scores between different states of cognitive decline. Spearman correlation analysis showed that social support was positively correlated with cognitive function, especially naming (r = 0.161, p < 0.05) and attention (r = 0.246, p < 0.01). Mental health was negatively correlated with attention (r = -0.327, p < 0.01).

**Conclusions:** There is a correlation between cognitive function, social support, and mental health in middle-aged and elderly people. Therefore, it is essential to pay attention and early intervention for patients with poor mental health status and social support.



# Association between Social Support and Cognitive Impairment among Chinese Community-dwelling Older adults: A cross-sectional Study

Dr Yuan Fang<sup>1,2</sup>, Prof Xia Li<sup>1</sup>

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#### **Topic**

Dementia risk reduction: Risk factors

### **Abstract**

**Objectives:** The main objective of this study was to investigate the association between social support and cognitive impairment in older adults aged 55 years and above who reside in the community. Additionally, the study aimed to explore the potential mediating effects of depression and anxiety on this relationship.

**Methods:** A total of 834 participants aged 55 and older were included in the study. Cognitive function, social support, depression, and anxiety were assessed using the MoCA, SSAS, SAS, and GDS scales, respectively. Participants were categorized into cognitively normal and cognitively impaired groups based on MoCA scores and education level. Various logistic regression models were employed to analyze the associations between SSRS scores and cognitive impairment and causal mediation analyses were conducted to explore whether anxiety and depressive symptoms mediated these associations.

**Results:** Social support was found to significantly reduce the risk of cognitive impairment (OR=0.581, 95% CI, 0.429-0.789, p<0.001) in older adults. Importantly, this relationship remained significant even after controlling for factors such as age, sex, education, APOE $_{\epsilon}4$  carriage, anxiety, and depressive emotions. Additionally, it was observed that anxiety and depressive symptoms among the elderly played mediating roles in the association between social support and cognitive impairment. The proportions of mediation were calculated to be 6.74% and 12.17%, respectively.

**Conclusions:** This study, based on community-based data in Shanghai, provides valuable insights into the impact of social support and emotional factors on cognitive impairment among elderly individuals. These findings contribute to a better understanding of the relationships between social support, emotions, and cognitive health in older adults.



# Effect of a group-based acceptance and commitment(ACT) intervention Reduces the Risk of Dementia in Middle-Aged and Elderly Patients with Schizophrenia

Mrs Wan-Yun Meng

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### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

The aging of society is a global trend, and previous research has found that middle-aged and elderly patients with schizophrenia are at a higher risk of developing dementia. Currently, it is known that ACT group therapy interventions can effectively enhance the self-esteem and psychological resilience of individuals with schizophrenia. The purpose of this study was to investigate whether ACT group interventions could reduce the risk of dementia in middle-aged and elderly patients with schizophrenia. This research employed a pre-post design with assessments conducted before and after the group intervention. Participants included individuals aged 50 to 65 with chronic schizophrenia and AD-8 scores of 2 or higher. Various assessment tools, such as self-esteem scales, frontal lobe assessment scales, and the Philadelphia Mindfulness Scale, were used to measure participants' self-esteem, self-acceptance, self-awareness, and cognitive function. Statistical analysis was conducted using SPSS 25.0 software, with a significance level set at p < 0.05. The results revealed that middle-aged and elderly individuals with chronic schizophrenia who received ACT therapy showed improvements in self-esteem, self-acceptance, and cognitive function.



Carbon monoxide (CO), and other products of combustion cause brain damage often misdiagnosed as Alzheimer's disease. But CO (and other products of combustion) can be prevented, so awareness and testing are vital to prevent/stop exposure.

#### **Mrs Stephanie Linda Trotter**

All Party Parliamentary Carbon Monoxide Group, London, United Kingdom

#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

Carbon monoxide (CO) is a product of combustion of any carbon-based fuel. CO is created when there is insufficient oxygen at the flame to produce carbon dioxide (CO2). CO cannot be sensed using human senses.

Less than 2% of CO in the air can kill in under three minutes. http://www.hse.gov.uk/foi/internalops/hid\_circs/technical\_osd/spc\_tech\_osd\_30/spctecosd30.pdf P. 26.

Lower levels of CO over time cause brain damage, see https://www.coresearchtrust.org/media-information/three-year-project-looking-at-risk-of-co-to-older-people-reveals-concerning-findings

Symptoms of CO are similar to any virus. Injury can be misdiagnosed as dementia/Alzheimer's.

In 1995, industry and government were reluctant to talk to us. Victims/survivors & families were not. One mother said, 'I didn't even know what CO was, so how could I have stopped my child dying of it?'

From 1995 we have collected & published data of unintentional deaths and injuries from CO see http://www.co-gassafety.co.uk/data/. Also, case studies https://www.co-gassafety.co.uk/case-studies/

Awareness is obviously vital. But without testing for CO, there is no proof of CO. Testing survivors is unreliable. Medics think CO incredibly rare. Proved CO was rare, due to lack of testing. Therefore, data was/is also lacking.

Testing is now being done in homes of 'vulnerable customers' by ¾ of the gas emergency service in the UK https://vimeo.com/727002257/939926c093. But everyone is vulnerable to CO, however healthy wealthy or wise. **Testing air needs to be done, whenever practicable.** 

Small, respected university studies show over 20% of UK homes\* have 50 parts per million (PPM) of CO or above. WHO guidelines are 4 PPM in 24 hours. https://www.co-gassafety.co.uk/about-co/numbers-affected-by-co/

\*Extrapolates to 13 million people in UK.



# Smoking cessation duration and cognitive function among middleaged and older adults in China

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** Aging and smoking are both significant global concerns, particularly in developing countries. This study aims to explore the potential relationship between smoking cessation duration and cognitive function in middle-aged and older Chinese.

**Methods:** The data comes from China Health and Retirement Longitudinal Study (CHARLS) 4th wave. Smoking information was collected by standardized questionnaire. MMSE and CERAD word recall test were used to evaluate cognitive function. Using restricted cubic spline (RCS) to explore curvilinear relationship. After discretizing the duration of ex-smokers (quitting ≤2 years, 3-8 years, 9-19 years and ≥20 years), multiple linear regression models were established with current smokers as reference.

**Results:** A total of 5561 respondents (67.7 $\pm$ 6.2 years; 54.1% men) were included. RCS showed that respondents who quit smoking for longer performed better global cognitive function. This trend leveled off among respondents who had quit smoking for  $\geq$ 20 years. There were significant differences in global cognitive function among those who quit smoking for  $\geq$  9 years (9-19 years,  $\beta$ =0.75, 95%Cl 0.32 to 1.18;  $\geq$ 20 years,  $\beta$ =0.94, 95%Cl 0.42 to 1.46). The differences mainly came from men. In immediate memory, all ex-smokers performed better (P<0.05). In delayed memory, only those quit for  $\geq$ 9 years had significant differences (9-19 years,  $\beta$ =0.33, 95%Cl 0.02 to 0.63;  $\geq$ 20 years,  $\beta$ =0.50, 95%Cl 0.12 to 0.87).

**Conclusions:** Compared with current smokers, both never smokers and ex-smokers performed better cognitive function. Respondents who quit smoking for longer had better cognitive performance, especially those who had quit for at least 9 years.



# Establishing an innovative Brain Health Service and Clinic in Scotland: Initial evaluation and audit findings

Mrs Helen Skinner<sup>1,2</sup>, Ms Sara Di Stefano<sup>1</sup>, Mr Hugh Masters<sup>1</sup>, Mrs Linda Duthie<sup>3</sup>

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#### **Topic**

**Dementia risk reduction:** Risk reduction and prevention (including clinical trials)

#### **Abstract**

In December 2023 a new Brain Health Service and Clinic will open in Aberdeen, Scotland. This is a unique collaboration between Alzheimer Scotland, Brain Health Scotland, Scottish Government and NHS Grampian Public Health. The service supports people to understand their risk of dementia, provides early disease detection, and offers personalised action plans for dementia prevention. A unique aspect of the project is the ability for people to self refer or walk-in to the Brain Health Service. Direct referral to the Brain Health Clinic can be made by General Practitioners. Every individual will have their risk-factors for dementia assessed and be given advice on dementia prevention.

An evaluation of the development of the service and the service effectiveness is underway. The evaluation is using mixed methods to gather data. A questionnaire was issued to the stakeholders involved in the planning, design and development of the Brain Health Service and Clinic. Qualitative interviews were conducted with a purposive sample of key members of the service development process. Finally standardised audit data is being collected for all those attending or referred to the service or clinic.

- This presentation will describe the preliminary findings, in particular:
- Identification of perceived challenges and facilitators in adopting and developing a Brain Health Service and Clinic
- Stakeholders' level of motivation and engagement with the project
- Understanding of the purpose and benefit of the Brain Health Service and Clinic
- Alignment of the Brain Health Service and Clinic with existing practices
- Key indicators important for measuring the success of the Brain Health Service and Clinic
- Service and clinical audit data

The conclusions will present a comprehensive picture of how the Brain Health Service and Clinic have been developed, perceived and adopted, the decision-making processes that influences these factors, the initial effectiveness of the service and lessons learned to date.



# The influence of social connection profiles of older adults on mental and cognitive health and functional ability in the Older Australian Twins Study

Dr Anne-Nicole S. Casey, Dr Suraj Samtani, Dr Anbupalam Thalamuthu, Dr Ben Lam, Dr Vibeke S. Catts, **Prof Henry Brodaty**, Prof Perminder S. Sachdev

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#### **Topic**

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

#### **Abstract**

**Aims:** Use data from older adult twins to investigate whether heritability influences the type of social connections that people focus on, and whether specific types of social connections promote better mental and cognitive and functional health over time.

**Method:** We used data from 599 people 65 years of age or older (333 monozygotic and 266 dizygotic twins) who completed interviews/assessments at three timepoints as part of the Older Australian Twins Study (OATS). Social connection profile type (e.g., friends, family, community, caregiving) was determined using factor analysis. Structural equation modelling was used to identify associations between profile type with depression and anxiety symptoms, and with cognitive and functional ability scores, controlling for multiple covariates.

**Results:** Social connection variables did not show significant heritability. In fully adjusted cross-sectional models, people who had profiles focused on friends/neighbours and community reported fewer depressive symptoms (-0.107, p=.029), better functional ability (-0.134, p=.019) and better language scores (0.139, p=.01). People who had family and child/grandchild care-focused profiles had poorer language scores (-0.154, p=.003), and people whose profiles focused on other caregiving activities/ religious groups/community had better executive function scores (0.091, p=.035). Age, sex, education, depression, diabetes, hypertension, smoking and alcohol consumption were associated with cognitive scores. Social factors did not influence whether symptoms of depression or anxiety or cognitive or functional abilities changed over time.

**Conclusion:** Social connection profiles were not heritable. People who focused on engaging with friends, neighbours and the community reported better mental and cognitive health and functioning in the moment, but the type of social relationships did not effect change in mental and functional health over time in this study. Health care for older adults should include screening for social connections and providing tailored information about social connections that promote healthy brain ageing.





### V32-001

# **Exploring the Feasibility and Related Factors of Applying Information System to Support Dementia Case Management**

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#### **Topic**

Information systems for dementia: Global Dementia Observatory (GDO)

#### **Abstract**

Integrating the resources of dementia care into dementia case management is considered a crucial progress of a long-term care policy development. In order to assist in assessment, planning, and health education for case management, dementia case managers need an appropriate information system to ease dementia case management. It is important to investigate the feasibility and related factors of a supportive information system to dementia case management. Our study designs a novel analytical method based on the Technology Acceptance Scale (TAS) and semi-structured interviews. This method can analyze the quantitative data using descriptive statistics, one-way analysis of variance (ANOVA), Pearson's correlation, and multiple regression analysis. In addition, this method uses the content analysis on those qualitative data to percept the user experience of dementia case managers after they operated the supportive information system. According to the analytical results by our method, it is notable that the age of dementia case managers is the most correlated attribute to the adoption of supportive information system from the ease-of-use viewpoint. On the other hand, to explore the related factors of using a supportive information system, the analytical results showed that the work relevance is a significant predictor which can determine the overall technology acceptance with a regression variance of 78%. As observing the user experience in terms of age and work relevancy, it is able to differentiate the efficacy and usefulness by different dementia case managers that perform the dementia case management with an supportive information system. Hence, our study provides an applicable method for investiging the feasiblity of a supportive information system of dementia case management. Based on the practical use experience of dementia case managers, a friendly information system can expedite the dementia case management with a joint effect of time-saving and high quality of care management.



#### V33-001

### Widening access to STrAtegies for RelaTives (START), an effective and cost-effective intervention for family carers, in the UK and globally.

**Dr Tiffeny James**, Dr Penny Rapaport, Prof Gill Livingston University College London, London, United Kingdom

#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

#### **Background:**

Improving access to appropriate support for family carers is a key global dementia priority. Family carers are more likely to experience anxiety or depression than non-carers, and their psychological morbidity predicts breakdowns in care.

STrAtegies for RelaTives (START)

START, developed in the UK, is a manual based therapy for family carers of people living with dementia, delivered by supervised, non-clinically trained workers. It is proven to be clinically and cost-effective and saves money in the UK while reducing anxiety and depressive symptoms and increasing quality of life for family carers. It has lasting efficacy and carers receiving it are five times less likely to have clinically significant depression after six years than the control group.

Widening access to START

START was culturally adapted for UK-based South Asian and Black families. This version was acceptable and feasible, and changes in mental health were in line with those in the original trial. The adapted version is now used with people from any background as the adaptations e.g., making pictures ethnically diverse and discussing who in the wider family START should be shared with, benefit people from any background. Despite its evidence base, START is not widely available in the UK. We are exploring the feasibility of a social enterprise dedicated to rolling out START in the UK with potential for international roll-out through a hybrid training package for facilitators with implementation support. START has already been translated into Japanese, Portuguese, Spanish, Macedonian, and several South Asian languages. It has been piloted in Australia, Japan, Spain, and India and will soon be piloted in Macedonia and Brazil. We plan to partner with researchers in lower- and middle-income countries to widen access to START globally.

**Conclusion:** START is a scalable evidence-based intervention which can be implemented internationally.



#### V33-002

# A randomised controlled trial of the effectiveness of the World Health Organisation's e-health resource 'isupport' for dementia caregivers

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#### **Topic**

Support for dementia carers: Education and training for informal carers

#### **Abstract**

The WHO recommends access to affordable, proven, well-designed, online technologies for education, skills-training and support for dementia carers. In response to these recommendations, this multisite randomised controlled trial (RCT) is the first study in the UK to evaluate the effectiveness of an online support programme developed by the WHO called 'iSupport' for dementia carers.

A target sample size of 350 was required to achieve 90% power and accommodate 25% attrition. Informal carers (age 18+ years) living in Britain who self-identified as experiencing stress and depression were recruited through Join Dementia Research, partner organisations and the NHS. They were randomised to receive 'iSupport', or standardised information (control–comparison). Data were collected via videoconferencing (e.g, Zoom) or telephone interview at baseline, 3 months and 6 months. Intention-to-treat analysis ascertained effectiveness in the co-primary outcomes (distress and depression), secondary outcomes (anxiety, resilience, dementia knowledge and relationship quality). Combined cost and quality-adjusted life-year data assessed cost-effectiveness compared with usual care from a public sector and wider societal perspective.

352 people were recruited. Attrition was 24.4%. Data collection ended October 2023. The final analysis will be completed January 2024 and shared for the first time at this conference. It is hypothesised that 'iSupport' will be cost-effective and reduce distress, depression and anxiety and increase resilience, dementia knowledge and relationship quality.

Online carer interventions are appealing to service providers in terms of their low-costs and potential scalability/reach, and to carers who can access them when they want, from a place convenient to them, and are able to work at their own pace. The potential for wide-scale implementation is highly relevant as few education/support programmes, particularly e-health interventions for carers, are widely implemented outside a research setting. This RCT provides a definitive test of iSupport, which is being implemented globally by the WHO.



## Relationship-Centered Care in Fictional Autobiography between Patient with Alzheimer's Disease and Caregiver: insights from a Moroccan Novel

#### **Prof Mohamed Taiebine**

The Euro-Mediterranean University in Fez (UEMF), FEZ, Morocco

#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Aims:** About My Mother (2016) is a novel written by French-Moroccan author Tahar Ben Jelloun. It traces Moroccan history during the colonial and post-colonial periods while addressing many multicultural issues pertaining to women's situations, aging, and sacred femininity. This study aimed to analyze relationship-centered care as well as caregivers' ambivalent resilience, caring, and coping with two antagonist characters incarnated by Lalla Fatma (from an Eastern Arabic perspective) and Zilli, who symbolizes the Western European approach.

**Methods:** The themes of spirituality, sacred femininity, and the burden of Alzheimer's disease (AD) endorsed by Lalla Fatma and her caregivers were described using a neuro-aesthetic and psycho-social approach. Quality of life was summarized by contrasting the informativeness of their discourses on various subjects such as religiosity, spirituality, daily life, forgetfulness, and burnout of caregivers.

**Results:** The narrator and his mother's relationship-centered care exemplifies a symbiotic dyad. The caregiver triad (son, daughter, and family) and Lalla Fatma are cornerstones of successful coping. She was able to adjust to the disease with ease and dignity, thanks to an effective salutogenic strategy based on humaneness. The narrator also depicts the intercultural and intracultural characteristics of conventional and emancipated woman figures by contrasting their lifestyles on the two sides of the Mediterranean Sea.

**Conclusion:** Sacred love and quasi-religious regard for parents were shown in many dyads from Western and Eastern perspectives. Throughout the narrative discourse, Ben Jelloun discussed the utopian character of oriental and family centered care. He implied overlapping links between Alzheimer's disease and personal, medical, and sociocultural elements impacting Lalla Fatma's life story.



### Meaning-Making of Dementia Caregiving: a systematic review of qualitative studies

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#### **Topic**

Support for dementia carers: Informal carers support – pre, during and post

#### **Abstract**

**Background:** Being the backbone of informal care, the caregivers of people with dementia in their daily dementia caregiving have suffered psychological, physical, and financial burdens without effective coping strategies. Meaning-making of dementia caregiving experiences promotes caregivers' psychological and physical well-being as well as the quality of care provided. However, without reaching the consensus of conceptual understanding of critical components and phases within meaning-making framework, the effectiveness of meaning-making-related interventions cannot be consistently and reliably examined. This study systematically reviews the evidence on meaning-making of dementia caregiving experiences and thus aims to identify 1) critical components constituting meaning-making framework, and 2) critical phases of the meaning-making process.

**Methods:** Registered on PROSPERO, this systematic review identified 62 qualitative studies published in four major databases between 1969 and 2022. Eligible studies were identified based on the criteria of PICOS. The screening process complied with PRISMA. The risk of bias was evaluated using the CASP. By using thematic analysis, critical components and phases of meaning-making were deduced from the extracted thematic content.

**Results:** Synthesized meaning-making components included (1) complicated demands and personcentered care, (2) evolving dynamics of relationships (dilemma in familial relationship, and ambivalence in dyadic relationship), (3) coping and adapting (loss and growth, complied and integrated values, balance between expectations, and self-efficacy). The meaning-making process included phases of (1) meaning creation to make sense of the overwhelming dementia caregiving experiences, (2) meaning appraisal processed via assimilation and accommodation, and (3) meaning adherence for reappraisals of critical meanings.

**Discussion:** Findings reveal that meaning-making of dementia caregiving experiences is a multi-faceted and multi-phased recursive process. The findings highlight the potential urge to depict a clearer conceptualization of meaning-making components and procedure, on which relevant measurements can be accurately designed while existential interventions can be developed.



## Crossing the Line: Understanding the experiences of family carers who provide personal care for someone with dementia

Dr Shirley B Evans, Mrs Faith Frost, Mrs Pauline Finlay, Prof Dawn Brooker

University of Worcester, Worcester, United Kingdom

#### **Topic**

Support for dementia carers: Informal carers support - pre, during and post

#### **Abstract**

The Association for Dementia Studies at the University of Worcester was granted 18-month funding by the UK National Institute of Health and Care Research to conduct the study Crossing the Line. The study commenced in December 2022, with the aim to gain a deep understanding of the experiences of family carers relating to their provision of care to people living with dementia.

Family carers often face challenges adapting to the role that providing personal care brings, and this can be worsened by lack of knowledge and skills, information, shame and embarrassment. The challenges around personal care are often a tipping point for the person living with dementia to move into a care home. Personal care includes helping with going to the toilet, washing, bathing, dressing, mouth-care, shaving, haircare, foot and nail-care though initial research showed that little is known about it in the context of dementia and family care.

The findings from the study enabled the development of resources and education around personal care for family carers. The project has a strong patient and public involvement aspect running throughout and a range of stakeholder perspectives, including from family carers, informed the development of the research.

A UK-wide survey exploring the insights of 500 dementia family carers about their experiences of delivering personal care, their coping mechanisms, and the impact it may have on their wellbeing were conducted. This informed the topic guide for interviews conducted with 45-50 family carers.

In addition to statistical analysis of survey findings, Interpretive Phenomenological Analysis was used to make sense of qualitative data.

Three co-production workshops with families and professionals were held, enabling the development of a core set of pilot training materials for testing and evaluation with family carers.

In this poster presentation the key findings and conclusions from the study will be presented.





# To what extent does the daily frequency of BPSD in the person living with dementia influence the caregiver's sense of burden over 28 days?

Ms Megan Sheehan<sup>1</sup>, Dr Audrey Duceppe<sup>2</sup>, Ms Lea-Maude Leblond<sup>1</sup>, **Dr Jean Vezina**<sup>3</sup>

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#### **Topic**

**Support for dementia carers:** Informal carers support – pre, during and post

#### **Abstract**

**Aim:** This study examined the daily variation in selected BPSD manifested by people living with dementia and their caregivers' sense of burden.

**Methodology:** To achieve this objective, caregivers were asked to keep a daily diary for 28 consecutive days. The daily journal enabled us to better capture the actual frequency of BPSD in the home, document daily variations and measure their daily impact on caregivers. Caregivers were asked to note the appearance of certain BPSD described during a previous individual interview. They were also asked to indicate how much the observed behaviour bothered them on a Likert scale ranging from 0 (not at all) to 4 (extremely). The abbreviated version of Zarit's burden inventory was also completed over the 28 days. The sample consisted of 27 family caregivers (mean age = 66.81 years) of people with dementia recruited from the community.

**Results:** Multilevel analyses confirmed the hypothesis that the impact on caregivers was more significant on days with more BPSD. All three classes of BPSD identified in this study were associated with caregiver subjective burden. These behaviours were in the following order of importance: aggressive behaviours, agitation behaviours and apathy.

**Conclusion:** Observing daily variations in BPSD and feelings of burden in the caregiver provides a better understanding of the caregiver's day-to-day life, enabling more precise intervention.



#### V35-001

#### Long COVID-19 symptoms in MCI and Dementia

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#### **Topic**

**Dementia research and innovation:** Younger onset, Mild Cognitive Impairment (MCI) and mild dementia

#### **Abstract**

**Introduction:** Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. What is its impact though on people with Mild Cognitive Impairment (MCI) or dementia?

**Methods:** Self-reported questionnaire was used for the report of the Long-Covid 19 symptoms, regarding the duration, the exact symptoms, and the amount of the effect. People with MCI or dementia or their caregivers regarding patients' health were recruited from the Athens Alzheimer's Association.

**Results:** Our sample consisted of 56 participants. Twenty-two (39.3%) had the diagnosis of MCI, while 34 were people with dementia. Most of the people reported symptoms of Long Covid-19 for 3-4 weeks. Strong were all the symptoms reported (problem in breathing, fatigue, sore throat, and psychological distress/ depression), with the majority of the people answered the questionnaire reporting fatigue as the major disturbance. This was followed by the "Psychological distress/ depression". The symptoms affected people significantly, with almost 40% reporting "Quite enough" disturbance.

**Discussion:** Long Covid-19 is reported to be similar to other geriatric syndromes, in that the exact mechanism that leads to the symptoms is complex and not clearly understood. Therefore, the diagnosis and the management of the Long Covid-19 symptom requires a more holistic and comprehensive approach.



#### V36-001

## Increasing Carer performance and Carer Wellness through Spiritual Intelligence

#### Mr Basantsingh Deerpaul

Pranalife, Flacq, Mauritius

#### **Topic**

Support for dementia carers: Young carers

#### **Abstract**

In the last few decades interest in spirituality has been expanding, particularly within patients facing life menacing as well as neurodegenerative conditions. As part of the holistic approach to patient care, the relevance of Spiritual Intelligence also addresses healthcare practitioners and carers wellness.

Amongst leading definitions, spiritual intelligence may be characterised as "the adaptive use of spiritual information to facilitate everyday problem solving and goal attainment. Usually, the five components of spiritual intelligence are:

- 1. The capacity to transcend the physical and material.
- 2. The ability to experience heightened states of consciousness.
- 3. The ability to sanctify everyday experience.
- 4. The ability to utilize spiritual resources to solve problems.
- 5. The capacity to be virtuous.

With the rise in the symptoms' complexity of Dementia, patients' caregivers seem to face several challenges that seem to affect their physical and mental health.

Evidence linking Spiritual Intelligence or Spiritual Quotient (SQ) with work is highlighted scantily through studies examining the causal relationship of spiritual intelligence on work performance among nurses chiefly. When Spiritual intelligence is applied at work, performance increases despite being confronted daily with multiple occupational stressors. Secondly, spirituality provides meaning and purpose to life.

And thirdly, nurses who develop their own spirituality can reflect it in their practice, through trusting and empathetic relationships.

Nurses share similar work characteristics with Carers and since SQ has been successful in a related field, the same paradigm may be extended amongst other healthcare fellows.

#### The aim of this paper is two-fold:

- To highlight that SQ is a philosophy that may be adapted to Dementia Carers' training and eventually to work experience and
- Explore the possibility for research into Carers' wellness especially for those working with persons living with Dementia.



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Below are the original abstract numbers, which can be used to find the relevant **programme** code.

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58

13-001

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198	I10-004
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390	I10-006
489	I10-007

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322	V3-001

190	V4-001
199	V5-001
705	V5-002
49	V6-001
297	V6-002
331	V6-003
481	V6-004
546	V7-001
289	V8-001
576	V8-002
622	V8-003
108	V9-001
298	V9-002
552	V10-001
149	V10-002
287	V10-003
316	V10-004
364	V10-005
473	V10-006
653	V10-007
471	V11-001
119	V12-001
589	V12-002
697	V12-003
29	V13-001
290	V13-002
446	V14-001
293	V15-001
344	V16-001
572	V16-002
105	V17-001
474	V17-002
22	V18-001
23	V18-002
156	V18-003
458	V19-004
174	V20-001
116	V21-001
117	V21-002

237	V21-003
768	V21-004
81	V22-001
107	V22-002
173	V22-004
189	V23-001
466	V24-001
233	V25-001
724	V25-002
24	V26-001
39	V26-002
127	V26-003
469	V27-001
620	V27-002
767	V27-003
259	V28-001
301	V29-001
330	V30-001
449	V30-002
616	V30-003
654	V30-004
118	V31-002
281	V31-003
300	V31-003
664	V31-005
754	V31-006
262	V32-001
299	V33-001
338	V33-002
318	V34-001
392	V34-002
395	V34-003
537	V34-004
421	V35-001
723	V36-001