



33rd International Conference of Alzheimer's Disease International

26 – 29 July 2018, Chicago, USA



Abstract book

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 Alzheimer's Disease International



**Alzheimer's Disease
International**

The global voice on dementia



PLENARY ABSTRACTS

Plenary 1: International and national policy

Date: Friday, 27 July 2018

PL1-001

LIVING WITH THE PLAN

Mr. Jerry L Wylie*, Dementia Alliance International, Philomath, OR

Abstract:

Jerry is an advocate living with dementia. Jerry will share his personal perspective on his involvement in contributing towards the development of the National Plan to Address Alzheimer's disease through his work with Ian Kremer (LEAD). This session will address the following key points: momentum achieved in development and implementation of plan; inclusion of individuals impacted by dementia; importance of funding to achieve plan goals.





PLENARY ABSTRACTS

Plenary 2: Scientific progress

Date: Friday, 27 July 2018

PL2-001

ALZHEIMER'S DISEASE RESEARCH YEAR IN REVIEW: SELECTED HIGHLIGHTS AND IMPLICATIONS FOR THE FUTURE

Alireza Atri¹, Research, Banner Sun Health Research Institute, Phoenix, AZ

Abstract:

This brief plenary lecture will use selected highlights to provide an up-to-date review of AD research in the last year and suggest implications for future research, therapeutics, and care. Topics reviewed will include research findings in: 1.) AD biomarkers and diagnostics, such as learnings regarding the spatiotemporal dynamics and hierarchical progression of AD biomarkers (Gordon BA, et al. Spatial patterns of neuroimaging biomarker change in individuals from families with autosomal dominant Alzheimer's disease: a longitudinal study. *Lancet Neurology*, March 2018), preliminary evidence to support the utility of amyloid PET imaging in clinical practice (Rabinovici G, AAIC 2017; de Wilde A, et al.

[Association of Amyloid Positron Emission Tomography With Changes in Diagnosis and Patient Treatment in an Unselected Memory Clinic Cohort: The ABIDE Project](#). *JAMA Neurol*. 2018 Jun 11), and advances in tau PET imaging; 2.) AD pathogenesis, such as evidence to support that Herpes Virus (HHV-6; HSV1 and HSV2) viral load is linked to activation of gene networks in preclinical AD that may drive production of A β (Readhead B, et al.

[Multiscale Analysis of Independent Alzheimer's Cohorts Finds Disruption of Molecular, Genetic, and Clinical Networks by Human Herpesvirus](#). *Neuron* 99, 1–19 July 11, 2018); 3.) New AD definition as a biological construct for use in interventional and observational research, as put forth in the NIA-AA New Research Framework via the ATN classification schema (Jack CR Jr, et al. NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimers Dement*. 2018 Apr;14(4):535-562.); 4.) Therapeutic AD clinical trials, such failures of several large programs (e.g. BACE-inhibitors; 5-HT₆ antagonists; RAGE-inhibitor), advances for promising programs (e.g. anti-tau passive antibodies; GENERATION program), and encouraging preliminary reports and trends (e.g. aducanumab removes brain amyloid; higher doses of passive amyloid-beta antibodies being tested in clinical trials); 5.) Dementia prevention, such as support from The Lancet Commission Report that ~35% of dementia may be preventable through treatment of modifiable risk factors (Livingston G et al.

[Dementia prevention, intervention, and care](#). *Lancet*. 2017 Jul 19); and 6.) New evidence-based Clinical Practice Guidelines for the MCI, AD and dementia clinical spectrums (e.g. UK NICE June 2018 Dementia Guidelines; AAN MCI Practice Guidelines, Petersen RC et al. *Neurology* Dec 2017 epub ahead of print; First National Alzheimer's Association Best Clinical Practice Guidelines (AADx-CPG) for the Evaluation of Cognitive Behavioral Syndromes, Alzheimer's Disease and Related Dementias in the United States, Atri et al. AAIC 2018).



PLENARY ABSTRACTS

Plenary 2: Scientific progress

Date: Friday, 27 July 2018

PL2-002

MULTI-DOMAIN INTERVENTIONS TO PREVENT DEMENTIA: FROM CLINICAL TRIALS TO IMPLEMENTATION

Alina Soloman Dr*, University of Eastern Finland, Finland, Finland

Abstract:

Dementia and Alzheimer's disease are complex multifactorial conditions with many modifiable risk factors, e.g. lifestyle-related, cardiovascular, or metabolic. Prevention strategies targeting multiple risk factors and disease mechanisms simultaneously may be most effective. Such strategies are needed for different populations, and geographical, cultural and economic contexts.

The Finnish Geriatric Intervention study to prevent cognitive impairment and disability (FINGER) included 1260 older people with increased risk of dementia, but without substantial cognitive impairment. This was the first large, longer-term randomised controlled trial to show cognitive benefits for a 2-year multi-domain lifestyle intervention (nutrition, exercise, cognitive training and social activities, and cardiovascular risk monitoring) versus regular health advice. The intervention also had benefits on health-related quality of life, everyday functioning, and multimorbidity in this at-risk general population.

Following the success of the FINGER intervention model, the World-Wide FINGERS initiative was launched in July 2017. This is a worldwide collaborative network of clinical trials and experienced investigators to facilitate harmonization of research methods, and sharing of experiences and data for maximum global scientific impact. Several clinical trials in e.g. Europe, USA, China, Singapore will adapt and test the FINGER model in different populations and settings, from community level to patients with early stage (prodromal) AD.

Implementation of dementia prevention activities from a clinical trial setting into real life is also needed. The MUISTIKKO project in Finland is currently taking the first steps in this direction, by focusing on the development of an operational model for dementia prevention. Some of the key issues include identifying target groups for prevention programs, identifying facilitators and barriers to achieve and maintain healthy lifestyle changes, and close collaboration with the key stakeholders responsible for implementation activities.





PLENARY ABSTRACTS

Plenary 2: Scientific progress

Date: Friday, 27 July 2018

PL2-003

ALZHEIMER'S DISEASE RESEARCH UPDATE

Jeffrey Cummings MD*, Lou Ruvo Center for Brain Health, Cleveland Clinic, Las Vegas, NV

Abstract:

There are three major topics to be covered in this research update: (1) The advances in the staging of Alzheimer's disease (AD); (2) the use of the amyloid (A), tau (T), and neurodegeneration (N) biomarker approach to AD; and (3) emerging agents in clinical trials for AD.

Biomarkers have allowed the identification of preclinical and prodromal phases of AD. The preclinical phase lasts for 10-15 years during which there is minimal impact on cognition, aggregated A in the brain, and there is variable T and N. In a recent description of the preclinical through dementia phases of AD led by the FDA, six stages are recognized. Stage 1 has amyloid accumulation and no cognitive abnormalities; Stage 2 has minimal cognitive and no functional abnormalities; Stage 3 has mild cognitive abnormalities and minimally apparent impairment of Activities of Daily Living; Stages 4, 5, and 6 correspond to mild, moderate, and severe AD. Stage 2 can be conceptualized as early mild cognitive impairment (MCI) and Stage 3 as late MCI. Stages 2 and 3 correspond to the International Work Group (IWG) stage of prodromal AD.

The ATN Framework for AD allows a biomarker-based definition of AD independent of a clinical phenotype. "A" is characterized by a positive amyloid positron emission tomography (PET) or low A-beta 42 (A₄₂) in the cerebrospinal fluid (CSF). "T" is identified by a positive tau PET or elevated phospho-tau in the CSF. "N" is identified by elevated total tau in the CSF; hypometabolism on fluorodeoxyglucose (FDG) PET scan; or atrophy on magnetic resonance imaging (MRI). This framework will allow the identification of patient groups based on the underlying pathophysiology and may assist in accelerating clinical trials of disease-modifying agents.

There are approximately 112 drugs in clinical trials for AD. Three-quarters of these are disease-modifying agents and one-quarter of them are cognitive enhancers or psychotropic agents aimed at neuropsychiatric symptoms in AD. Disease-modifying agents include monoclonal antibodies, beta site amyloid precursor protein cleavage enzyme (BACE) inhibitors, and metabolic agents with a variety of mechanisms of action. Cognitive enhancing agents are exploring transmitter-based and ion channel interventions. Novel approaches to treatments of neuropsychiatric symptoms are evident in the AD drug development pipeline. Overall, there are too few agents in the AD pipeline and too few agents entering Phase I from laboratories; Phase I compounds comprise the future of AD therapies. Encouraging results from trials of emerging agents suggest that new treatments for AD are likely to emerge from the current pipeline.



PLENARY ABSTRACTS

Plenary 3: Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

PL3-001

FUNDING INNOVATION IN DEMENTIA DISCOVERY

Tetsuyuki Maruyama*, Dementia Discovery Fund, London, United Kingdom

Abstract:

Treating, caring for, and ultimately curing dementia must be one of the world's most important and urgent priorities. Yet sadly, progress in the discovery of new medicines has been disappointing. After many years of testing a relatively narrow set of hypotheses, it is time for the field to try a different set of approaches.

Innovation can be dramatically affected by the nature of funding for new ideas. Public funding bodies rely on peer review, which tends to reinforce existing ideas and can serve as a barrier to the entry of new entrants to an entrenched field. Funding through venture capital typically uses different criteria and different methods to identify and track projects and companies in which they invest, and so provides an opportunity to catalyse different thinking.

The Dementia Discovery Fund, established in 2015, seeks to fulfil this catalyst function by investing in new scientific ideas focused entirely on bringing about, as rapidly as possible, new and effective treatments for people with dementia. Like other venture funds, DDF's investors have high expectations for a return on their investment; unlike most other venture funds, the return they seek is more in clinical benefit than financial, and this gives DDF an opportunity to invest in longer-term, riskier ideas. Our focus is on the discovery of treatments that can bring durable symptomatic relief to dementia sufferers and their families, and our portfolio of investments ranges from very early and very risky projects to established early companies that are about to enter the clinic with truly novel approaches. Our short-term vision is an invigorated discovery environment in which venture backed biotech and large pharmaceutical companies are vigorously pursuing treatments for dementia. Our long-term vision is a world in which all patients with dementia can find the treatment they need.





PLENARY ABSTRACTS

Plenary 3: Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

PL3-003

AMONG ENGINEERS: NOTHING ABOUT US WITHOUT US

Mr. Michael Robert Belleville*, Dementia Alliance International, Bellingham, MA; Carole Mulliken M.Ed, Dementia Alliance International, Saint Charles, MO and Kate Swaffer Ms, Dementia Alliance International, Adelaide, SA, Australia

Abstract:

Although people with dementia are those most directly affected by the decisions policy makers and service providers make about dementia care, people with dementia are rarely involved in decision-making. ADI has led involvement efforts by including individuals with dementia on its own board of directors.

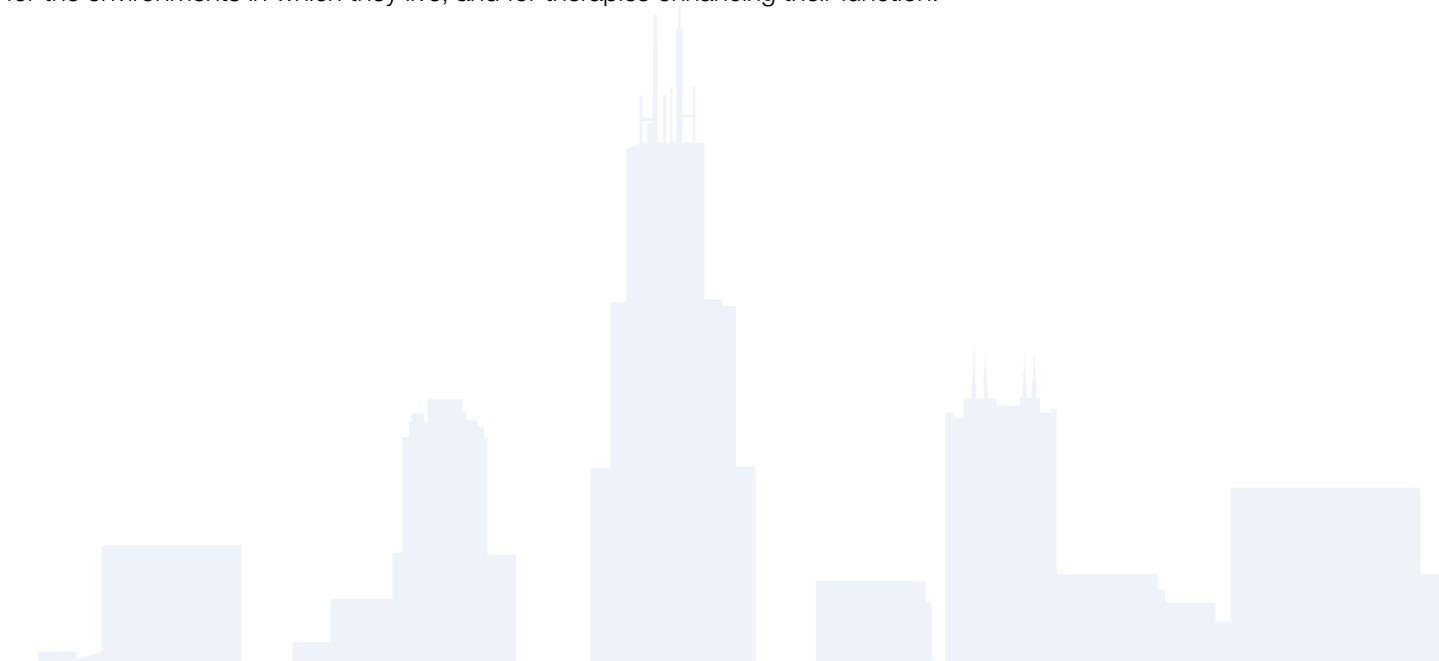
However, on many fronts, people with dementia have not yet been included. The Dementia Alliance International (DAI) was set up to ensure a more representative involvement of people with dementia. DAI asserts that development of new technologies for people with dementia will be significantly improved by including people with dementia in needs assessment, product planning, development, and field testing.

An exploration of the current development of technology devices and companies demonstrates that people with dementia are rarely, if ever, included in development of technology, or if they are, it is a very small cohort. DAI proposes an entirely new approach to technology development, which we will outline in the presentation.

People with dementia can help developers understand how the roles neuropsychological profiles, various memory types, sensory challenges, and differing types of dementia can play in technology development. We propose the development of collaborative teams of specialists who might increase the success of technologies under development.

Participants at this session will learn about three types of assistive technologies of interest to people with dementia and will hear a summary of the problems people with dementia confront with existing technologies. They will learn the way that we, the 'dementia experts' propose to be involved in novel collaborative teams for technology development.

Finally, reviews of a sampling of interesting technologies for people with dementia are offered for various devices, for the environments in which they live, and for therapies enhancing their function.





PLENARY ABSTRACTS

Plenary 3: Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

PL3-004

VIRTUAL REALITY CHANGING DEMENTIA CARE IN AUSTRALIA

Maree McCabe Ms*, Dementia Australia, Canberra, ACT, Australia

Abstract:

Traditional dementia awareness and care education methods have not had the desired impact on dementia care. Dementia Australia's team felt that more experiential education using virtual reality (VR) as a tool would give dementia care workers and family carers a more empathic understanding of dementia. This presentation will share learnings from concept development, consumer consultation, with video footage of the technology through to education outcomes.



With an estimated 50 million people living with dementia globally, in Australia 425,000 and with an estimated 1.2 million Australians involved in the care of people with dementia, the need for change is essential. Coupled with an ageing population and escalating demand in services, improvement in the care, health and lifestyle outcomes for all people impacted by dementia is vital.

With these objectives the world's first application of serious game technology in dementia care, the Virtual Dementia Experience™ (VDE), was developed to create an immersive, interactive virtual reality experience that invades the senses and takes people into the world of a person living with dementia - simulating thoughts, fears and challenges.

Launched in October 2013, the VDE™ has been experienced by more than 4,000 people including professional and family carers, healthcare professionals, high profile business and community leaders, architects, interior designers and Australian politicians; generated an extensive and ongoing media and social media conversation; has been presented and discussed at international conferences and has been recognised by national and international awards.

In 2016, EDIE- Experiential Dementia Immersive Experience was released that builds on the VR experience of VDE™, a mobile solution which can now be delivered nationally and internationally. Using the Samsung Gear VR platform, EDIE, is a unique learning experience that has been designed with a focus on teaching reablement to dementia care workers and increasing understanding and empathy in family carers.

Since the launch of EDIE in 2016 there has been enormous media interest nationally and internationally, including an interview on BBC World Service Click. Ongoing independent evaluation by Swinburne University ensures the approach is strongly evidence based, and forms part of a process of continuous improvement; delivering quality dementia education to improve the lives of those living with dementia.



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To date this research has found that in the VDE™ dementia care workers, when compared to participants in a non-virtual reality workshop, gained threefold more empathy for the person living with dementia, and were able to identify more dementia-friendly elements.

Family carer participant feedback indicates that family carers have gained a greater understanding of dementia, the impacts it can have and are reflecting on their caring role from the perspective of their family member living with dementia.

Now, our team combine the use of VR technology across a comprehensive suite of learning programs which are improving the quality of care provided to people living with dementia. Dementia Australia has become internationally recognised for its use of technology to aide learning. The team is driven by a strong desire to create unique learning experiences which touch, move and inspire participants to change the way they think, communicate and behave while also considering the care environment and thereby improving the lives of all those living with dementia.





PLENARY ABSTRACTS

Plenary 4: Care in dementia

Date: Saturday, 28 July 2018

PL4-001

#SEEME

Susan Ryan*, The Green House Project, Linthicum, ME

Abstract:

Imagine if you were labelled by only one word, and that word alone determined how the world treated you. The sum of your life experiences -- relationships, skills, unique perspectives -- would not matter. The complexity of what makes you unique as an individual would all be washed away by the one-dimensional perspective of that label. This is the reality for 5.7 million people in the USA alone, who are defined by their diagnosis of dementia, and that number is expected to rise to 14 million by 2050 (alz.org). This label focuses on what people can't do. On what's been lost.

According to the Population Reference Bureau, the aging of the baby boom generation could fuel a 75 percent increase in the number of Americans ages 65 and older requiring nursing home care to about 2.3 million in 2030, up from 1.3 million in 2010 (PRB, January 2016). Correlated with the increasing number of elders, is the prevalence of Alzheimer's disease, and the need for high-quality models that focus on the whole person, rather than the traditional biomedical model that focuses primarily on decline and disease. Costs of care for individuals living with Alzheimer's or other dementias are significantly higher than their counterparts without cognitive impairment. (Alzheimer's Association, 2017).

In response to data, and research demonstrating that 85% of people in Green House homes are living with dementia (Sharkey, 2011), the initiative developed an approach called, 'Best Life'. This approach is more than a check the box education, it is a process to transform the system and defy the stigma of dementia. Best Life is built on Green House core values of Meaningful Life, Empowered staff and Real Home. These values have shifted the paradigm of elder care to deinstitutionalize our thoughts. They serve as the strong foundation that is necessary to provide optimal and life-affirming memory care.

This keynote presentation will 'power-wash' your thinking through challenging and new ideas. We must destigmatize and humanize those living with dementia, in order to see the whole person first. Behavioral and Psychological Symptoms of Dementia (BPSD) is a term used to describe the following "symptoms" that occur in people with dementia: agitation, aberrant motor behavior, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes. A 2012 study found that 90% of people with dementia have BPSD (Frontiers of Neurology, 2012). What if instead, we said that 90% of people living with dementia will find themselves in a situation where their well-being is not adequately supported? How does that change the way we #SeeMe? Think about how any person might react in a similar situation, for example, a stranger coming to bathe them, and it becomes easier to view that reaction as an appropriate response to a broken system rather than a symptom of the disease.

We must answer the call to #SeeMe. Currently, there is no cure for dementia, all we have is culture, but that can be a powerful tool. When a person is deeply known and valued, it is possible to create a rich, meaningful life, full of purpose, growth and joy for every elder.

Now is the time to lead the way, address the stigma surrounding dementia, and support caregivers with the skills to see each elder as a unique individual, and to connect them to a meaningful life.



PLENARY ABSTRACTS

Plenary 4: Care in dementia

Date: Saturday, 28 July 2018

PL4-002

DEMENTIA FRIENDLY CITIES; AN EXPERIENCE OF CIVIL SOCIETY IN COSTA RICA AS A ROUTE OF THE FUTURE

Norbel Roman*, Costa Rica Alzheimer Association, COSTA RICA, Costa Rica

Abstract:

The Friendly City. Costa Rica.

Our Friendly City, is the city of Curridabat, located in the county with the same name, in Costa Rica. This county is divided into four districts. The city was declared "Friendly City" by the Local Government Council in May 2015, after the idea was implemented by the Alzheimer's Association of Costa Rica. The city of Curridabat has a population of seventy-six thousand. 12% of the population is over 60 years old.

The concept of Friendly City is one objective of the Alzheimer Plan of Costa Rica, and it is our commitment to launch this project. The Alzheimer Plan of Costa Rica was the first launched in a middle-income country, and the first one in Latin America. We believe that the ingredients needed to implement a Friendly City is work with impulse, to offer help, and then to keep working together.

Currently, there are nine main actions on which we are working in the city of Curridabat.

1. The Screening Program consists of a door-to-door survey, implemented by the Alzheimer Association with volunteers. Through this survey we were able to identify elderly people in risk of cognitive deterioration, and also caretakers in need of help. The results of the survey were shared with a Care Network of Public Health, for more assessment and for support. We also used Global Positioning tools.
2. 100% of the general doctors in the city of Curridabat were trained with updating clinics on dementia, and also with workshops about detecting early cognitive deterioration, and we also trained caretakers and considered their needs.
3. Risk reduction is a fundamental issue, and we had the idea of having two races with the subject of Risk Reduction, the races were called "Run For Your Memories".
4. There are various universities located in the Curridabat area. One of those is the "Santa Paula" University. This university is fully integrated with the idea of Friendly City, and they have helped with curriculum changes, with the organization of congresses, and even creating new careers: two classes of professionals have already graduated in Management of Dementia. Many of those professionals are already working in the field.
5. The said university is a leader in the field, at the Latin American level. Their help was fundamental when we developed and implemented the 9th Ibero-American Congress, with the participation of 90 speakers, 22 countries represented, and 13 regional ministry representatives.
6. We established the headquarters of the 10/66 Study of Costa Rica, in the city of Curridabat, with support from the university. We also created a Research Center to provide more support.
7. The local government of Curridabat is working with a community project called the House of Caretakers, which, when implemented, will provide support to all the caretakers of this country and neighboring counties.
8. There is a Project and a design for the first Transit Shelter for the Abandoned Elderly. This project is supported by the local government of Curridabat.



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9. We are working with a project of the Rest Center, which is a project to help and support the caretakers of the county, but still promoting the idea that the home is the ideal place for the elderly to live.

All these projects and actions are the objectives of the Alzheimer Association of Costa Rica. Our motto is "To Share Efforts". Therefore, we would like to share our efforts with other "Friendly Cities" anywhere in the world. Costa Rica wishes to have many more "Friendly Cities" in the future.





PLENARY ABSTRACTS

Plenary 4: Care in dementia

Date: Saturday, 28 July 2018

PL4-003

INTERGENERATIONAL HOME VISIT MUSIC PROGRAM IN INDONESIA

Amalia Fonk-Utomo*, Communication, Alzheimer's Indonesia, Groningen, Netherlands

Abstract:

The Background: In 2020 Indonesia will be ranked number 4 with people with dementia and in 2030 Indonesia will have one of the largest productive age generation in the world so caregiving is a thread for them. It covers both social and economic issues.

So the effect of dementia is beyond generations and we have started to engage them with several stimulations (meaningful engagement activities)

Home visits have been implemented in ALZI Jakarta's Chapter Program since 2016 and they have recently added music therapy as an intervention and collaboration between Alzheimer Indonesia, Atma Jaya University, Survey Meter, AdhiSvara Choir and several Youth Music-Dance Group with the support of Alzheimer Nederland through the ADI Twinning Program.

Music is known as one of the expressive therapies, consisting of a process in which includes all facets: physical, emotional, mental, social, aesthetic, and spiritual to help clients improve their physical and mental health.

The Method: Sadly, dementia is still a social stigma. Music intervention has been chosen to encourage youth participation to:

- Raise the awareness of dementia in young generation.
- Use music supported by young generation which stimulates PWD to be happier.
- Advocate the '10 signs of dementia'
- Start pursuing an active going out youth engagement initiatives in Indonesia and aim the biggest youth movement in Dementia Friendly Communities in Asia Pacific and real experience with PWD.

The pilot project duration was done in March until June 2018 in Jakarta with activities:

- Once a week Home visit to PWD and their Caregiver which is already being interview in advance (their favorite songs, caregiver challenge and consent)
- Once a month visit to Government Nursery Home and Private Nursery Home.
- Evaluate the happiness of PWD after being 'entertained' with qualitative method with survey meter.

The Result:

- Music shows the real character of PWD with their spontaneous reactions that leads more information to caregiver.
- Music is therapy for both PWD and Caregivers.
- For a country with massive musical diversity such as Indonesia this project shows opportunity to create more social, physical, emotional engagement through generations.



PLENARY ABSTRACTS

Plenary 4: Care in dementia

Date: Saturday, 28 July 2018

PL4-004

ESTABLISHING AND FUNDING LONG TERM CARE INFRASTRUCTURE

Anders Wimo*, Karolinska Institutet, Stockholm, Sweden

Abstract:

Given the enormous socioeconomic impact of dementia and the current and expected future numbers of people with dementia worldwide, any country needs a strategy to cope with this challenge. The WHO has also stated that dementia is a major public health issue.

Today almost 50 million people live with dementia. By ADI it is estimated that about 84% of people with dementia live at home and 16% in various types of care homes. However, there is a great variability globally. In Low and middle income countries, about 5% are estimated to live in care homes while 31% do that in high income countries. The costs of living in care homes is also a major cost component in the societal costs of dementia. The out of pocket payment for the families for care varies a lot worldwide, but for many families it is a great economic burden. In ADI's World Alzheimer Report 2013 the patterns of long term care in dementia were highlighted and OECD has also presented several reports on this issue. Long term care does not necessarily take place in large institutional settings; it can also be organized at home or in small scale care facilities. To simplify, the great challenge for high income countries is the funding of long term care, while the challenge in low and middle income countries is to establish an infrastructure for long term care and also to find ways in its funding. Since traditional care in institutional setting is very expensive and also has negative effects on those who live there, we challenge a great need to find new ways both for organising and funding long term care for people with dementia. In this presentation and the following presentations during this session all these aspects will be highlighted.





PLENARY ABSTRACTS

Plenary 5: Psychosocial interventions

Date: Sunday, 29 July 2018

PL5-001

LIVING WELL WITH DEMENTIA: FINDINGS FROM THE IMPROVING THE EXPERIENCE OF DEMENTIA AND ENHANCING ACTIVE LIFE (IDEAL) STUDY

Linda Clare^{*}, University of Exeter, Exeter, United Kingdom and **Keith Oliver**^{*}, 3 Nations Dementia Working Group, Alzheimer's Society, London, United Kingdom

Abstract:

'Living well' means experiencing a good quality of life, feeling satisfied with one's life, and having a positive sense of well-being. The Improving the experience of Dementia and Enhancing Active Life (IDEAL) programme was established to investigate how individual characteristics, social circumstances and psychological and material resources affect the possibility of living well with dementia and to help identify what can be done by individuals, communities, health and social care practitioners, care providers and policy makers to improve the likelihood of living well with dementia.

IDEAL is following the experiences of over 1500 people with dementia and their family carers throughout Great Britain over a six-year period. IDEAL is supported by a patient and public involvement network, Action on Living Well: Asking You (the ALWAYS group), which advises on various aspects of the programme.

This talk is jointly presented by Professor Linda Clare, who leads the IDEAL programme, and Keith Oliver, representing the ALWAYS group. Keith is active in advocacy work and in national and international discussions around dementia.

Linda will describe some of the main findings from the first stages of this ongoing programme. The IDEAL researchers began by exploring existing evidence about the aspects of people's experience that support or hinder the possibility of living well with dementia. The resulting systematic review included information from 198 studies and nearly 38,000 people with dementia. With input from the ALWAYS group, the researchers then developed a framework for examining influences on living well for people with dementia. They used this framework to analyse data from the first round of IDEAL interviews, conducted with 1547 people living with dementia, and find out which aspects of the participants' experience had the most influence on living well. The statistical information was enriched by individual narratives gathered in a smaller number of in-depth conversations.

Keith will reflect on his involvement and contributions to the IDEAL programme, and how the model of 'living well' resonates with his own experience.



PLENARY ABSTRACTS

Plenary 5: Psychosocial interventions

Date: Sunday, 29 July 2018

PL5-001

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PLENARY ABSTRACTS

Plenary 5: Psychosocial interventions

Date: Sunday, 29 July 2018

PL5-002

PSYCHOSOCIAL INTERVENTIONS FOR PEOPLE WITH DEMENTIA IN THE LOW AND MIDDLE INCOME COUNTRIES

Dr. Amit Dias*, preventive Medicine, Goa Medical College, Goa, India

Abstract:

There are more than 4 million people living with dementia in India and it is a major public health problem. The 10/66 dementia research group has conducted several epidemiological studies to highlight the extent of the problem in the Low and Middle Income Countries and also highlight the care arrangements, the needs and packages for care in these regions. Service development for people with dementia in India needs to take account of the fact that dementia tends to be poorly recognised, generally perceived to be part of normal ageing and families rarely present to health services due to stigma. The assessment and treatment that they receive is orientated towards acute rather than chronic conditions. Psychosocial interventions rarely reach the majority of people who need it and the treatment gap was estimated to be more than 90%.

We developed a unique programme to bridge the treatment gap for dementia and provide psychosocial intervention using lay health workers (non-specialist health care workers) under supervision. This was a task-shifting model which followed the principles of stepped care and high risk approach. We also had to ensure that the intervention was acceptable to those with low education and is culture sensitive. Involving locally available manpower to deliver the intervention at the door step of people with dementia also ensured the acceptability and scalability of the intervention. The psychosocial intervention addressed common behavioural problems, activities of daily living, balancing the family care, environment safety, and also involved components of management of chronic ailments such as diabetes, hypertension, nutrition and sleep. We conducted a Randomised Controlled Trial in 181 participants comparing the psychosocial intervention with enhanced usual care. The intervention proved to be very effective in reducing the stress in caregivers, their perception of burden and improved the quality of life in the people with dementia.

Psychosocial interventions are known to be as effective as the currently available pharmacological interventions. It can be made cost effective by task shifting and using non specialist health care workers under supervision. We propose to integrate the dementia home care intervention with the existing primary health care network using multipurpose health care workers for improving its outreach as mentioned in the Dementia India Report. This presentation will also cover the adaptation of Problem Solving Therapy and brief behavioural therapy for Insomnia for the prevention of depression in Late Life using creative flipcharts to improve engagement of the participants in the psychosocial intervention. Our future work involves the use of Technology to improve the delivery of evidence based psychosocial intervention.



PLENARY ABSTRACTS

Plenary 5: Psychosocial interventions

Date: Sunday, 29 July 2018

PL5-003

SOCIAL HEALTH AND ITS POTENTIAL FOR DEMENTIA RESEARCH AND PRACTICE

Myrra Vernooij-Dassen*, Radboud University Medical Center, Nijmegen, Netherlands

Abstract:

A number of psychosocial interventions in dementia have been found to be effective in regaining “lost functions” in persons with dementia and in enhancing sense of competence in their family caregivers. However, answers to why these interventions are effective in relation to dementia remain unclear.

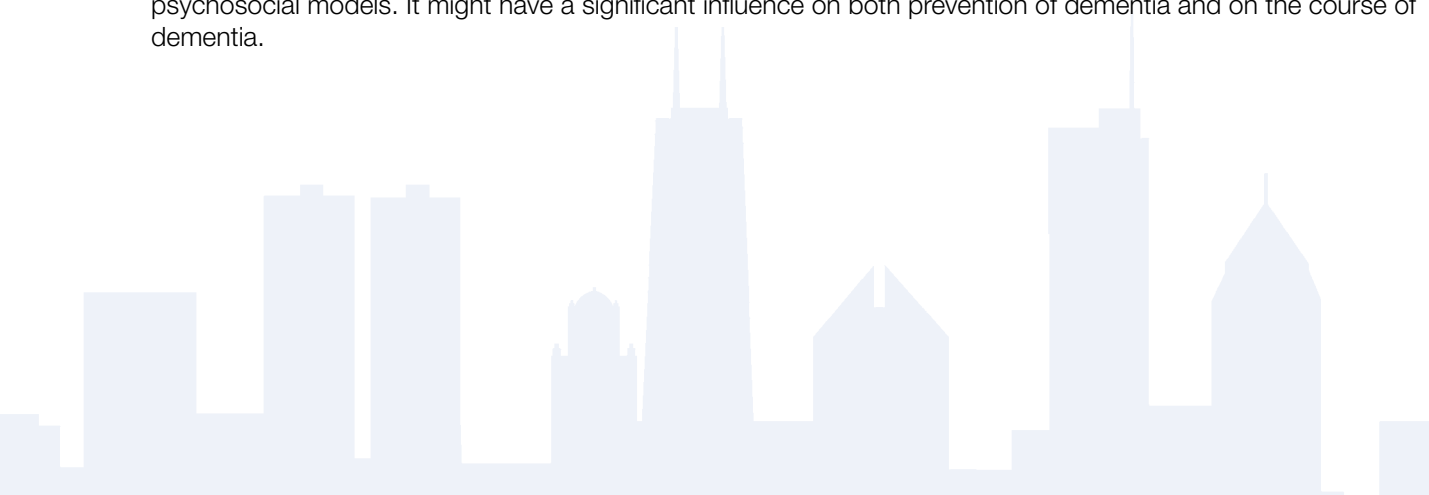
New avenues are needed to answer this question. Combining psychosocial and biomedical knowledge by studying the relation between social health and cognitive reserve offers a promising opportunity.

Social health has been conceptualized as the influence of social and environmental resources (including culture) in finding a balance between capacities and limitations. Cognitive reserve relates to the discrepancy between neuropathology and symptoms. Nearly 50% of people with dementia did not have sufficient neuropathology in their brain to explain their cognitive symptoms. High levels of AD pathology were present in one third of very old people without dementia. Cognitive reserve refers to the ability of the brain to actively withstand brain pathology by using pre-existing cognitive processes or by activating compensatory approaches.

We hypothesize that social health is a driver to use cognitive reserve through active facilitation and utilisation of social and environmental resources individuals possess and can have access to. This also implies the reverse: prohibiting utilization leads to underuse of cognitive reserve. Using and intervening in people’s social health will influence the dementia disease course.

Examples will be presented of active facilitation and utilization of social resources including engagement in joint activities such as making music and visiting a museum, supporting shared decision making and enhancing physical and cognitive functioning. Prohibiting the utilization of resources is called “prescribed disengagement”. Cultural variations can be observed around the world in the way of accepting people not being fully competent and allowing people to use their existing competencies. Cultures can learn from each other on how to promote social inclusion within ageing and dementia.

Exploring the potential of social health in dementia can contribute to better understanding the discrepancy between neuropathology and symptoms and advance our understanding as to why and how some people with dementia appear to regain ‘lost function’ following supportive psychosocial interventions. Social health might be a major resource for a breakthrough in the current paucity in dementia research when integrated in bio-psychosocial models. It might have a significant influence on both prevention of dementia and on the course of dementia.





INTRODUCTORY ABSTRACTS

Opening ceremony

Date: Thursday, 26 July 2018

IN1

THE IMPORTANCE OF ENGAGEMENT OF PEOPLE WITH DEMENTIA

John R Sandblom*, Dementia Alliance International, Ankeny, IA

Abstract:

This will be a presentation that explores the many ways of keeping people with dementia involved in many different types of things and reasons that diagnosed people should be included and utilized in many different ways. Our experience at DAI suggests that for many it can be a major boost in the quality of life to have a focus and purpose again after often believing that was impossible.

Some of the different areas explored will cover the use of support groups, being involved in volunteer work with a number of different options, participating in research studies, assisting in development and testing of new technology intended for PWD. Advocating in a number of different ways is also an option that will be covered. In the same thread as the motto we use “nothing about us without us” it should be stressed that it is also a basic human rights issue to be included in things that concern us. PWD being involved at many levels helps with the coping of the disease, improves quality of life and in many cases has benefits for both the carer and the public at large and these will be discussed.





INTRODUCTORY ABSTRACTS

Introducing the day

Date: Friday, 27 July 2018

IN2

STIGMAS - A MARK OF DISGRACE

Christine E Thelker Ms., Dementia Alliance International, Vernon, BC, Canada

Abstract:

In my perfect world I would like everyone to start seeing me the person, not Dementia the illness. My perfect world can't exist in a world filled with stigmas. I want to speak to the stigmas that keep this from happening.

When you have Dementia, most friends and family don't want to know, they don't want to ask, they don't want to see. They fall by the way side because of their own lack of knowledge and willingness to sit down and ask what a day is like for me. Example: Family who want to hide Diagnosis.

I think it is, in part, the responsibility of the person diagnosed to advocate for themselves, educate and teach about their illness. It is equally the responsibility of family and friends to learn all they can to ensure the person lives the best life possible.

We desperately need more education on all levels to help the health care community realize: Dementia is not the Person. Example Immediate loss of job, no longer included in planning.

The medical profession must listen to those who have Dementia because they are their most effective teachers. They should have an active voice in all curriculum used and how it is taught throughout the medical profession. Example: New Nursing Aid thinks patients won't know if she makes a mistake.

Many organizations are seeking funds, without any input from clients. This perpetuates the view of the people making the decisions and not the actual people living with Dementia. Example: Alzheimer's Society reaction to my CBC radio interview.

I pledge to keep using my voice and I implore you to help bring this Stigma to an end.





INTRODUCTORY ABSTRACTS

Introducing the day 2

Date: Saturday, 28 July 2018

IN3

MOTHER AND SON

Maria Louise Turner* and **Rhys S Dalton Mr***, Dementia Alliance International, Simpsonville, SC

Abstract:

In this presentation, we will present on the roles of a young woman with younger onset dementia and her young carer, facing dementia together. Rhys will discuss and explore the role and impact of being a young man, in the early stages of his career and life, whilst taking on the responsibility of caring for his mother. Maria, his mother who was diagnosed with younger onset dementia aged 48 will then discuss the feelings and challenges this presents as a parent, alongside the challenges of living with dementia. The changes that dementia brings with it, mean that the roles are often talked about as if they have been reversed, using phrases such as 'my mum has become my child' or 'I have had to become the parent'. In our experience, whilst as the one sibling who is also a carer (with my fiancé) I have had to take on many of the physical responsibilities my mother once was able to do, but we have fought to keep our roles of parent and adult child separate from dementia, so that we can focus on our love and relationships, rather having them defined only by dementia. We have defined ourselves as we always have, that is, meaning she is still my mother and I am still her son. We will close our presentation with a shared statement of love and respect for each other, and how dementia has made us much closer.





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WORKSHOP ABSTRACTS

ADI workshop - Fundraising

Date: Friday, 27 July 2018

W1-001

WALK AROUND THE WORLD TO HELP END ALZHEIMER'S DISEASE (AND OTHER DEMENTIA): A FUNDRAISING PROJECT

Dina Newsom¹; Hollie Fowler¹ and **Mr. David Troxel**², (1)Prestige Senior Living, Vancouver, WA, (2)Best Friends Approach, Sacramento, CA

Abstract:

This presentation describes how one senior living company, and its Celebrations program for elders, raised more than \$80,000 for the US Alzheimer's Association. The presentation will describe the fundraising project and recommend ways to replicate the program to benefit dementia programs anywhere.

The fundraising campaign, *Step Up to End Alzheimer's*, challenged residents and staff across all Prestige Care communities and corporate headquarters to walk (over the course of one month) 65 million total steps – the approximate distance around the globe – while also raising funds to benefit the Alzheimer's Association. Residents and staff collected donations from family, friends, and local businesses by pledging to reach personal step goals and participating in events and activities throughout the month of September, with every penny of the \$80,000 raised donated directly to the Alzheimer's Association.

As part of the *Step Up to End Alzheimer's* campaign, residents and staff at nearly every community across the company's eight-state footprint kept track of their steps to reach weekly goals, which were measured out to various locations across the world – including Greenland's Ilulissat Icefjord, Mt. Kilimanjaro in Tanzania, Sydney Harbor in Australia, and ending at the Golden Gate Bridge in San Francisco, California.

Residents and staff participated in a variety of fun events including "walkathons" and community-based exercise classes to get moving and achieve their goals. Staff joined in the fun, too, and participated in activities while keeping track of their residents' steps and charting their progress around the world.

The presentation will materials and timetables from the project and suggest ways to produce a local program with superior results. The program can be easily adapted to a variety of settings and had only minimal start-up costs.

Results: The program raised significant funds for Alzheimer's services and research while encouraging wellness and exercise as part of the company's Celebrations program for independent and assisted living residents. Goals are meaningful for all of us, including elders and persons living with dementia. The Step Up to End Alzheimer's Campaign allowed residents to create and meet fitness goals, experience purpose and civic engagement, enjoy socialization with others, fostered inter-generational efforts and helped our company's residents be healthy and happy.



PARALLEL SESSION ABSTRACTS

Awareness and stigma

Date: Friday, 27 July 2018

1-002

WHAT WOULD I WANT? DEMENTIA PERSPECTIVES AND PRIORITIES AMONGST PEOPLE WITH DEMENTIA, FAMILY CARERS AND SERVICE PROFESSIONALS AND THEIR IMPLICATIONS FOR PUBLIC HEALTH CAMPAIGNING

Irja Haapala^{1,2}; Simon Biggs^{1,3} and Ashley Carr⁴, (1)School of Social and Political Sciences, The University of Melbourne, Melbourne, VIC, Australia, (2)The University of Eastern Finland, Savonlinna, Finland, (3)The Brotherhood of Saint Laurence, Melbourne, Australia, (4)School of Social and Political Sciences, The University of Melbourne, Melbourne, Australia

Abstract:

Objectives: To examine whether there are distinctive priorities and attitudes, based on closeness to dementia, between people with dementia, carers, health and welfare plus commercial service professionals. To identify priorities for effective public campaigning in relation to dementia based on these perspectives. To elucidate the importance of familial proximity in relation to counteracting stigma and for perceptions of dementia in the public sphere.

Methods: We conducted semi-structured interviews with people with dementia (n=19), carers/support persons (n=28), health care professionals (n=21), social workers (n=23) and people who worked in service professions (e.g., hairdressing, hospitality and other customer service staff and entrepreneurs) (n=20), in five Australian states, in 2017; plus with campaign originators (n=20) in Australia and abroad, in 2018. Participants were asked about: first impressions of dementia, what they would want for themselves, what a good campaign should cover and how the general public perceived dementia. Interview recordings were transcribed into Microsoft Word, imported into NVivo 11 and coded by the two interviewers with high inter-coder reliability. NVivo Query Matrices were run to identify clustering of campaign priorities followed by in-depth narrative analysis of content using triangulation between three researchers. SPSS non-parametric and parametric tests were used for comparisons between groups, and Excel was used to illustrate the findings. For the analysis, participants were grouped based upon 1) perspective: a first (people with dementia), second (carers) and third person (professionals) perspective, and 2) closeness based on personal or family connection (proximity) to dementia. Research was undertaken with ongoing advice from the Dementia Consumer Network based at Dementia Australia and ethically approved by the University of Melbourne Humanities and Applied Sciences Human Ethics Sub Committee (HESC 1647136).

Results: Contrasts were found between the priorities of the different perspectives, plus a common feeling that dementia should become a normal part of social life. People living with dementia were distinctive in their concern for dignity and social inclusion, with carers focussing on support and understanding. A key factor emerges as being whether service and care professionals had a family connection with dementia. However, rather than reflecting stigmatising behaviour, all professional groups expressed a need for knowledge on how to communicate and interact with people with dementia. In contrast to current campaigns, information on prevention and priorities based on health systems were a low priority. Campaign originators' views lent support to those of the consumer groups.

Conclusions: Results indicate the need for more precise targeting of priorities in public campaigning and an emphasis on day-to-day interaction and social inclusion. Family proximity emerged as an important factor for professional and public empathy in future campaigning and interventions.



PARALLEL SESSION ABSTRACTS

Awareness and stigma

Date: Friday, 27 July 2018

1-003

NORTHWESTERN UNIVERSITY *BUDDY PROGRAM* INCREASES MEDICAL STUDENT KNOWLEDGE, EMPATHY, AND ATTITUDES TOWARDS PERSONS LIVING WITH DEMENTIA

Dr. Darby Morhardt*, Cognitive Neurology and Alzheimer's Disease Center, Northwestern University, Chicago, IL

Abstract:

Objective: Approximately 13.3% of the current US population is aged 65 and older and projected to double by 2060. Age is the greatest risk factor for dementia. It is important that medical students are equipped with appropriate knowledge, skills, and attitudes to meet the medical needs of this aging population, including exposure to and understanding of dementia. The *Buddy Program* is an experiential learning program that pairs first-year medical students with persons with dementia for a year of activities and relationship-building. Objectives are to educate students about dementia by a) enhancing dementia knowledge, b) introducing the spectrum of capabilities of persons with dementia, c) providing opportunities to observe how persons with dementia adapt throughout the disease progression, d) familiarizing students with care and support for persons with dementia.

Method: Pre- and post-test data from 202 first-year medical students who participated in the *Buddy Program* were collected and analyzed for responses to: 1) NU Dementia Knowledge Test (n=149 pre-intervention, n=129 post-intervention), measuring familiarity with dementia, 2) Jefferson Empathy Scale (n=44 pre-intervention, n=40 post-intervention), measuring empathy, 3) Dementia Attitudes Scale (n=44 pre-intervention, n=37 post-intervention), measuring attitudes towards those with dementia, and 4) Stigma in AD Scale (n=16 pre-intervention, n=18 post-intervention), measuring stigma associated with AD. Statistical comparisons were conducted via paired t-test.

Result: There were significant increases in medical students' knowledge of dementia (6.5% increase in NU BP Dementia Knowledge test, $p<0.0001$), empathy towards those with dementia (12.2% increase in Jefferson Empathy Scale, $p<0.0001$), positive attitudes towards those with dementia (13.5% increase in Dementia Attitudes Scale, $p<0.0001$). There was also a statistically significant decrease in stigma towards those with AD (12.5% decrease in the Stigma in AD Scale, $p=0.023$).

Conclusion: This study demonstrates that experiential learning programs such as the *Buddy Program* can significantly improve knowledge and attitudes towards those with dementia while also reducing stigma. Results suggest this program may serve as a model for improving knowledge of similarly stigmatized conditions while enhancing understanding of what it means to live with chronic disease.



PARALLEL SESSION ABSTRACTS

Awareness and stigma

Date: Friday, 27 July 2018

1-004

AWARENESS OF THE IMPACT OF A PRISON REGIME FOR OFFENDERS WITH DEMENTIA: SUPPORTIVE OR DESTRUCTIVE?

Joanne Mary Brooke Dr* and Debra Jackson Prof, OxIMNAHR, Oxford Brookes University, Oxford, United Kingdom

Abstract:

Objectives: The prison population is aging, and the prevalence of dementia of prisoners has increased. Tentative figures from the United States suggest 40% of prisoners over the age of 55 have some degree of cognitive impairment (Williams et al. 2010). However, research studying dementia in prison populations is limited. The aim of this study was to explore the current knowledge and skills of staff, prisoners and volunteers involved in the care and support of prisoners with dementia.

Methods: A qualitative phenomenological design was applied. Interviews and focus groups were conducted in the prison setting with both staff and prisoners. Staff included: healthcare professionals from mental health and primary care services, social workers, probation officers, educationalists, and prison service staff, including disciplinary officers, instructional officers, and members of the chaplaincy. Prisoners included those with special roles such as buddies, listeners or those that attend groups developed for older prisoners (social inclusion and diversity). Interview schedules were developed to ensure consistency of data collection. The interviews and focus groups explored experiences of supporting prisoners with dementia, and were audio recorded and transcribed verbatim. Thematic analysis as described by Braun and Clarke (2006) was completed.

Results: Setting: a category C male prison in the South of England, UK. Data were collected during September – December 2017, via focus groups (n=10) and interviews (n=5) with a total of 38 participants, including: prison officers (n=8), probation officers (n=3), educational staff (n=3), mental health nurses (n=2), social workers (n=3), primary care staff (n=5), and prisoners including: buddies (n=4), listener (n=1), and members of social inclusion (n=5) and diversity (n=4). Three themes emerged from the data: Development of health and social care in prison: are we just playing at it? Assessing and understanding behaviours: we are not trained in that type of stuff? Impact of dementia on prisoners and the prison service: all we can do is keep them safe, keep the regime running. The main discrepancy between the views and beliefs of staff and prisoners was the impact of the prison regime for prisoners with dementia, staff expressed supportive views, whilst and prisoners expressed the prison regime could be destructive.

Conclusion: Staff believed it was easier to care for people with dementia in the prison setting, due to well-established regimes, and held the belief that prison was a supportive environment for people with dementia as there was less risk for accidental self-harm. Whereas prisoners who had had completed a training programme to support fellow prisoners with dementia (buddies) had a greater insight into the needs of this population. Buddies discussed a disrupted prison regime, which had a destructive impact on prisoners with dementia, and they felt they were left 'firefighting' to try and bring their fellow prisoners back on an even keel. Further education and training is required to develop a united understanding on how to better support prisoners with dementia. An integrated workshop, including prison staff, health and social care professionals and prisoners with specialist roles needs to be developed to enable consistent and appropriate support for prisoners with dementia. There is a further need for a structured process to communicate the concerns and changing needs of this population amongst this multi-disciplinary team.



PARALLEL SESSION ABSTRACTS

Awareness and stigma

Date: Friday, 27 July 2018

1-005

CHALLENGING THE STIGMA OF DEMENTIA: BUILDING A MOVEMENT

Ms. Maria Howard*, Alzheimer Society of B.C. , Vancouver, BC, Canada

Abstract:

The Alzheimer Society of B.C. is committed to building a world where people living with dementia, their caregivers and families are included, acknowledged and supported – a truly dementia-friendly society. In order to build that world, we need to move away from fear and denial of the illness, towards awareness and understanding. When we reduce stigma, people affected by dementia can live better.

Negative attitudes held by friends, family and professionals can often discourage people from getting a diagnosis, seeking treatment and support or disclosing their illness. According to a Leger-led online survey conducted by the Alzheimer Society of Canada, 46 per cent of respondents said that they would feel ashamed or embarrassed if they had dementia and 61 per cent felt they would face discrimination of some kind. Recently, the Canadian Dementia Priority Setting Partnership identified the impact of stigma as the number one priority for Canadians affected by dementia.

Only by challenging stigma about dementia can we build a caring and inclusive community for individuals and families affected by dementia. During this presentation, the presenter will touch on the ways that the Alzheimer Society of B.C. is addressing stigma to build a community of care, including:

- Informing the public how they can play a role in building a dementia-friendly province.
- Engaging with and amplifying the voices of people affected by dementia as spokespeople, advocates and advisors, bringing their lived experience and leadership to the forefront of the Society's work.
- Establishing successful partnerships with municipalities who are working towards building dementia-friendly communities across British Columbia.
- Challenging stigma by implementing innovative, culturally specific strategies in under-served communities.
- Promoting and supporting research with the ultimate goal of improving the lives of people affected by dementia.





PARALLEL SESSION ABSTRACTS

Awareness and stigma

Date: Friday, 27 July 2018

1-006

“THE BRAIN STRENGTHENING LOHAS BUS” - A MOBILE CLINIC TO STRENGTHENING PEOPLE’S BRAIN, SCREENING FOR AD AND MCI AND EDUCATING PEOPLE IN REMOTE COUNTRY SIDE IN TAIWAN

Cheng Hsiu Chuang*;Meng Hsiu Chung;Yu Xiang Lin;Keith H. Chen;Yin Fu Chen;Cheng Kai Wen;Di Ya Hsieh and Wei Chiao Ke, ADLers Occupational Therapy Clinic, Taipei, Taiwan

Abstract:

As one of the fastest aging society in Asia, Taiwan will turn to aged society from aging society in 2018. The population of people who suffer from Alzheimer’s Disease(AD) is dramatic increasing. According to the Ministry of Health and Welfare in Taiwan, about 8% of people are suffering from AD at the age above 65. There are about 260,000 people who has AD in 2016, and estimate there will be more than 850,000 people would have AD and MCI in the next 40 years.

The government of Taiwan has planned a lot of therapeutic groups for MCI or dementia patients in the city center. However, those who live in the country side and remote area were not that lucky.

The New Taipei City, which is located around the Taiwan’s Capital-Taipei City, is one of the biggest city in Taiwan, which has lots of remote country area. The unbalance medical resource between the city center and the remote country also cause big problem with people who suffer from the AD. Since lots of young people move into the city center for study and work, most of the elderly people still live in the country side. The condition is getting worse from time to time. It would be a huge burden both the medical resource and financial of Taiwan.

The Department of health of the New Taipei City Government (NTCG) has came out with a new idea. They cooperated with a innovative occupational therapy clinic (ADLers Occupational Therapy Clinic), that has both OT and PT with lots of experience and familiar with AD patients and has lots of innovative way of treating patients. After months of planning and preparing, they has built up a very interesting bus with specially design to carry tons of therapeutic aid, board games ,cognitive assessment tools and the most of all – 2 therapists on board.





PARALLEL SESSION ABSTRACTS

People call it “The Brain Strengtheners Lohas’s Bus. The Lohas Bus started its journey on the November 2017, it travels to 2 remote country sides per day 3 times a week. And host a Brain strengthening fair twice a year. They cooperate with local health center and community care centers. The therapists design a complete process of therapeutic activities, including screening (finding potential MCI or AD patients), cognicising (cognition and exercise) and therapeutic activities such as board games, video interactive game, Tai Chi, handicraft and singing to strengthen people’s brain. In just 3 months, The Lohas Bus had traveled to more than 10 remote country side and served thousands of people. It was a great impact for those elderly people who has never came across of those brain strengthening game and activities. Since the Lohas Bus came to their village, because the interesting program and the brilliant skill of the therapist, Lohas Bus really catch their eyes and make them willing to come out the door to join the activities. The Lohas Bus activated people’s life wherever they go. Meanwhile, those therapists not only brought energy to the village, but also screened and educated people about the knowledge of health and AD.

Each time, therapist led the activity about 2 hours. After class, people could even rent the board games, books about the health and AD home. It has become a trend and a big event in lots of people in remote village in Taiwan. The Lohas Bus change people’s life in Taiwan and help government to find out lots of MCI and AD patient and started their treatment in the early phase. Which make people to have the right treatment and lower the cost of government on AD’s medical care.

The Bus will keep hitting the road in Taiwan and helping more and more people.





PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-001

WHICH COMES FIRST--THE CHICKEN OR THE EGG?: DEMENTIA-FRIENDLY AND AGE-FRIENDLY COMMUNITIES CROSS-POLLINATE

Sarah Lock^{*}, Policy, Research & International, AARP, Washington, DC, DC; **Mrs. Stephanie K Firestone**^{*}, International, AARP, Washington, DC, DC and **Fei Sun**^{*}, School of Social Work, Michigan State University, East Lansing, MI

Abstract:

Over 550 communities are current members in the WHO Global Network of Age-friendly Cities and Communities (over 200 in the U.S. alone), with potentially thousands more communities that use age-friendly guidelines and tools created by WHO and AARP to structure similar local initiatives outside this framework.

Along similar lines, at the 70th Session of the World Health Assembly in May 2017, WHO adopted the Global Dementia plan, which outlined seven areas for actions including promotion of dementia friendly initiatives in different countries. According to the report of Alzheimer's Disease International, 35 countries have a dementia-friendly initiative in place. In the U.S., about 28 states have a dementia friendly community initiative.

Age-friendly and dementia-friendly initiatives both aim to help older adults remain independent within the community as long as possible, by creating a supportive enabling environment. Additionally, they engage with broad coalitions of stakeholders from civil society, business and government as well as elders, to strengthen community supports and increase inclusion for the benefit of people of all ages. However, age-friendly strategies benefit older adults or people with disabilities more generally, while dementia-friendly actions and design features tend to focus on a specific set of needs of individuals and family caregivers affected by dementia.

The parallel emergence and evolution of both types of initiatives has created some confusion around whether it is most appropriate and how best to integrate the two, or how to reap the greatest benefit from separate but coordinated initiatives. It also raises questions around the ideal order for engaging in these efforts, i.e., which comes first—the chicken or the egg? Varying approaches to integration have included: age-friendly and dementia-friendly are aligned and incorporated into broader city plans; a dementia-friendly plan is incorporated into an age-friendly plan, and both initiatives enjoy high level city support; or regional guidance connects age- and dementia-friendly efforts. This session's authors find that the most constructive conversation to be had is around how these approaches can complement rather than compete with one another.

This session will present brief overviews of dementia-friendly and age-friendly initiatives and tools available for executing each, including the process of creating a WHO dementia-friendly initiatives toolkit. Next, the authors will present recommendations developed by AARP around how these two types of initiatives can complement one another. Finally, the presentation will highlight some updated case studies in different parts of the world illustrating the different models that communities are using to undertake both, and share lessons learned thus far through these disparate approaches.





PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-001

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PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-001

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PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-002

CREATING DEMENTIA FRIENDLY COMMUNITIES THROUGH STAGING PLAYS

Ms. Meera Pattabiraman*, ARDSI, Kerala, India

Abstract:

A novel method which proved very successful in creating dementia awareness and friendliness was adopted in the state of Kerala by staging plays on dementia. Sponsored by the State Department of Social Justice, the national office of Alzheimer's and Related Disorders Society of India (ARDSI) conducted a week long programme traversing a distance of 560 kms.

The programme started in the northern most part of Kerala and culminated in the state capital, Trivandrum, covering 2 districts per day. The title of the project was 'Ormakkootam', which means memory gatherings. The 2 hour long events, at all the fourteen places, included awareness talks by doctors and ARDSI staff, followed by the play and closed with an interactive session with the audience.

The play named "Achan" which means father was about an elderly person with dementia being taken care of by a paid carer. Though this carer was not professionally trained, with his compassion and common sense he provides loving care to Achan. The father's role was enacted by a renowned stage actor Sivaji Guruvayur, whose mother has Alzheimer's disease and being a carer, he wrote the script based on his own real life experiences. The play highlighted many of the symptoms of dementia and the audience was not only enlightened about dementia, they were also moved to tears about this condition which has so much stigma and discrimination.

The valedictory function in Trivandrum was graced by the Minister of Health and Social Welfare and she promised her whole hearted support to the Kerala State Initiative on Dementia which is the first public private partnership for comprehensive awareness, training and providing care services.





PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-003

LEVERAGING EXISTING STRENGTHS TO BUILD DEMENTIA FRIENDLY COMMUNITIES: THE NEED FOR IMPROVED DEMENTIA LITERACY

Kathleen V Doherty*; Claire Eccleston; Susanne Becker and Helen Courtney-Pratt, Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, Australia

Abstract:

Objective: Community action is essential to assure people living with dementia remain connected, included and enjoy quality of life. Tasmania, Australia's island state, has the oldest population in Australia with almost 20% of residents over 65 years of age. Coupled with its regional status, projected dementia figures suggest that Tasmanian communities will need to prepare for increasing numbers of residents with dementia. Here we explore how a range of demographically diverse communities envisage moving toward a future which includes and supports those living with dementia.

Method: Twenty workshops were held in rural, regional and urban communities across Tasmania. These facilitated workshops explored participant perceptions of their communities, the existing strengths and resources of the communities and the ways in which these could be mobilised with a view to becoming more dementia friendly. Data collected at the workshops was explored qualitatively to expose themes common to these groups and identify priority needs.

Result: Over 300 community representatives attended the workshops. These included people with dementia, carers, care-workers, aged care providers, health professionals, local government, volunteers, community services and interested members of the public. Participants framed dementia friendly communities as, safe, inclusive, connected and enabling choice. Existing strengths were informed in part by a history of resilience, that included a "just do something" attitude, a willingness to act, a capacity to circumvent red tape and intergenerational connections. Accessible information about dementia, and effective ways to build community knowledge in the context of an intergenerational framework were seen as important enablers of inclusion and support for people living with the impact of dementia. Together this suggests that even in the presence of willing people, suitable environments, and collaborative relationships there remains a need for improved dementia literacy, as a foundation for change.

Conclusion: Communities have a wealth of skills, resources and relationships, often honed through the need to meet other community challenges, which can be leveraged when building dementia initiatives. Improving cross generational dementia literacy was universally seen as an essential step toward building on these strengths. Importantly any action was viewed not only to benefit those living with the impact of dementia, but also to benefit the wider community.





PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-004

BUILDING A DEMENTIA-FRIENDLY NEW ZEALAND

Catherine Hall* and **Ngaire Dixon***, Alzheimers New Zealand, Wellington, New Zealand

Abstract:

Dementia is one of New Zealand's most significant healthcare challenges. Our response is to strive for a society where people living with dementia are included, valued, empowered to contribute and participate, where they have access to the services and support they need, and where they feel safe. This paper describes Alzheimers NZ's dementia friendly programme suite designed to generate change by engaging with individuals, businesses, organisations and communities. We have taken a 'learning by doing' approach to this work seeking to transform our broader community. The voices of people living with dementia are strongly represented in these initiatives, ensuring their right to determine their future is well and truly heard. Supporting them with a range of practical services also remains at the core of what we do, including through our network of local Alzheimers organisations throughout the country. This paper describes our development journey to date of four related programmes aimed at generating transformational change.

Our Dementia Friendly Recognition programme for businesses and organisations launched in 2017. Seven dementia-friendly standards; person-centred, leadership, workforce, physical environments, workplace, collateral and websites and planned review, need to be met to earn formal recognition as a dementia friendly organisation. Businesses and organisations enrol, complete an action plan, provide a self-assessment and supporting evidence and undergo an audit. Six businesses have been awarded Dementia Friendly Status, eleven are enrolled with some about to go undergo audit. A further seven are considering joining.

The Dementia Friends programme engages individuals to learn about dementia and how they can help. To become a dementia friend, they complete a short education programme and make a commitment to take a dementia friendly action. No action is too small. No action is too big. We plan to recruit 5000 Dementia Friends in 2018 and double that in 2019.

Through the Dementia Friendly Communities programme, we work with communities to find ways to better support their residents living with dementia. Rotorua is committed to and actively working on their dementia friendly action plan. We support and contribute to this work. Rotorua Library and Customer Centre have enrolled in our Dementia Friendly Recognition Programme. Two further councils are interested in joining.

We have developed new Services and Standards which specify a set of core services that Alzheimers NZ organisations should be offering, and a set of standards against which these services are measured. This model is based on the rights of people living with dementia to high quality support and services, no matter where they live, or who provides those services. The views of people living with dementia are integrated with research and emerging evidence about what makes a difference to their health and wellbeing. In 2018 we expect to have 15 services enrolled.

Our programmes are part of the growing social movement helping to increase awareness and create positive change. Our strategy is to generate the impetus for change at individual, business, organisation and community levels. We have made a promising start and expect to build transformational change at community and society levels. We are taking an active learning by doing approach. Our journey is important. The voices of people with dementia and what we learn along the way are informing and teaching us as we go.



PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

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PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-005

ENHANCING THE RESPONSE TO THE BURDEN AND IMPACT OF DEMENTIA THROUGH POLICY AND INNOVATION

M. Walid Qoronfleh Dr.; Maha El Akoum; Sanaa Alharahsheh and Feras Al Meer, Research & Policy, Qatar Foundation, Doha, Qatar

Abstract:

Dementia is not one disease, but a term that describes a range of symptoms. It is associated with an overall decline in memory or other cognitive impairments, such as judgment, orientation, calculation, and language, all of which inhibit an individual's ability to perform everyday activities (1). Most dementia are progressive, and symptoms often get worse gradually. The disease is caused by damage to the brain cells that then interferes with the ability of brain cells to communicate. While there is no one single test to determine if someone has dementia, doctors often diagnose based on medical history, physical examination, laboratory tests and changes in thinking, daily function and the expression of different behaviors that are associated with each type (2). Alzheimer's disease accounts for 60-90% of all dementia cases. There is no cure for dementia and no treatment that slows or stops its progression. There are, however, drug treatments and medications that can be used to temporarily improve symptoms (1).

Dementia has recently been declared a public health priority by the WHO as the population of the world and more specifically the developing countries is ageing rapidly now more than any time in history (2). Worldwide, the number of people living with dementia is estimated at 44 million, a number that is expected to double by 2030 and triple by 2050 (1,2). In the MENA region, the prevalence of dementia is expected to increase from 1.15 million in 2010 to 6.19 million by 2030 (2). In addition, the cost of care is extremely high and expected to exceed \$1 trillion annually in the US alone by 2050. Dementia is deeply devastating to families and caregivers that are affected by it, not to mention the tremendous financial strain that it inflicts on healthcare systems worldwide (1,2). Dementia is a growing concern in the Middle East, especially the Gulf Region including Qatar. WISH published its Dementia report in 2015. Since, dementia is one of the national health priorities in Qatar. Qatar is the **focal country for the Global Dementia Observatory (GDO-WHO)**. In addition, a **National Dementia Plan** is to be launched soon led by Dr. Hanadi Alhamad, Chair of the Geriatrics Department at HMC, and the local focal point for the dementia and the GDO.

To address dementia in a comprehensive way, the WISH Dementia Forum Framework presents three pillars that leads to improved outcomes for economies, society and individuals living with dementia. The WISH 2015 report entitled: "A Call to Action: The Global Response to Dementia Through Policy Innovation", introduces key issues in understanding the burden of dementia and policy recommendations that aim to tackle the burden globally and regionally. This research uses literature review and case study methods to identify and address different challenges associated with the increasing disease burden. Three main themes are explored, namely: prevention and risk reduction; diagnosis and care; and cure (1). It looks at solutions that are currently available and makes recommendations to policymakers to accelerate prevention, improve care and treatments, and potentially cure the disease. Finally, we highlight the role of public outreach and awareness to lay the groundwork for enlightened policy for intervention and resource allocation to care for dementia individuals.

References:

1. WISH Dementia Forum 2015, A Call to Action: The Global Response to Dementia through Policy Innovation, and WISH Meeting Report, 2016, Doha, Qatar
2. WHO Report 2012, Dementia, A Public Health Priority



PARALLEL SESSION ABSTRACTS

Dementia friendly communities - A

Date: Saturday, 28 July 2018

10-006

FINDING YOUR WAY: BUILDING SAFE COMMUNITIES FOR PEOPLE LIVING WITH DEMENTIA

Ms. Cathy Conway*, Alzheimer Society of Ontario, Toronto, ON, Canada

Abstract:

Sixty percent of people living with dementia-related memory problems become lost at some point. For many people, getting lost often happens without warning, as familiar surroundings may suddenly become strange to them, causing them to become disoriented and unable to find their way home. Becoming lost isn't just distressing; it can be dangerous. Fifty percent of people living with dementia who go missing for twenty-four hours or more risk injury or death from exposure, hypothermia or drowning. Would you know what to do if you came across someone who was lost or confused?

(Finding Your Way®) is a province-wide program developed in partnership with the Alzheimer Society of Ontario and the Ministry of Seniors Affairs. The program helps people living with dementia, their families and caregivers, and communities to recognize the risk of going missing, be prepared for incidents of going missing, and ensure that people living with dementia can live safely in the community. Since its launch in 2013, the program has become widely recognized for its role in addressing some of the toughest challenges facing people living with dementia, their families and communities. In addition to addressing the risks of going missing, the program has also recently expanded to encompass other safety-related concerns for people living with dementia.

Everyone has a responsibility to ensure that people living with dementia can live safely in the community, and while everyone faces some degree of risk, people living with dementia in the community face greater risks. Knowing the risks of living with dementia, reducing the risks, and having a plan are inherent to Finding Your Way's approach to ensuring people living with dementia can lead active, safe and engaged lifestyles, and taken together, can help foster communities that are dementia friendly.

This presentation offers an in-depth exploration of the safety challenges people living with dementia are facing today, including the risks of going missing and other critical safety issues. Practical strategies will be highlighted as a way of managing these risks. The importance of creating a safety plan and the resources Finding Your Way offers for inclusion in the creation of a safety plan will also be explored, such as an Identification Kit and a recently developed "Living Safely with Dementia Resource Guide" aimed at addressing critical safety issues for people living with dementia in the community and created in collaboration with one hundred and thirty-two people living with dementia and care partners, as well as other key stakeholders. In addition, this presentation will discuss the important role communities play, providing opportunities for reflection on what communities can do to ensure the safety of people living with dementia by: 1) knowing the signs; 2) knowing what to say; and 3) knowing what to do if they come across someone living with dementia in the community who is lost or confused.

Through the Finding Your Way program and other efforts, it is possible for people living with dementia to live safely in the community. By helping people living with dementia to live safely within the community, they are not only protected from adverse events – but their families have a greater sense of confidence, independence and dignity. Through a collaborative community effort and a primary focus on prevention, safe communities can be built for people living with dementia.



PARALLEL SESSION ABSTRACTS

Innovation showcase

Date: Saturday, 28 July 2018

11-001

IKEA DISCUSS THE IDENTIFICATION AND DEVELOPMENT OF NEW RANGE INITIATIVES ON A GLOBAL LEVEL

Britt Monti^{*}, Range & Design, IKEA of Sweden, Älmhult, Sweden

Abstract:

This presentation will talk about how the home furnishing company IKEA is working with Inclusive Design to approach the future living solutions for the ageing population. IKEA have developed a range of products called OMTÄNKSAM – which means caring in Swedish.





PARALLEL SESSION ABSTRACTS

Innovation showcase

Date: Saturday, 28 July 2018

11-002

ASSISTED SIMULATION APPLICATION USING A TRAIN CABIN SIMULATOR: INTEGRATING NON-PHARMACOLOGICAL WITH PHARMACOLOGICAL APPROACHES FOR DEMENTIA CARE

Konstantinos Petsanis Dr¹, Agnes Leotsakos^{*1} and Efthymios Papatzikis Dr², (1)Hôpitaux Universitaire de Genève, Genève, Switzerland, (2)Canadian University Dubai, Jumeirah, United Arab Emirates

Abstract:

An assisted simulation approach to using non-pharmacological and ambient therapies integrated with optimal medication prescribing practices can hugely benefit people living with dementia. Recent observations have shown the value of combining a balanced use of medications with assisted simulation using a virtual trip approach. This includes a simulated environment of a 'closed-space' that resembles a train cabin with a view to an interactive window which is, in reality, a computer monitor. A trip itinerary is presented in the monitor. The interactive environment simulates a train cabin using imaging, as the train passes through landscapes and cityscapes tailored to peoples' life experiences and needs. Beside visual inputs, the virtual trip is also designed to include sound, smell and touch inputs.

The people participating in this trip simulation, can be persons living with dementia alone, as well as healthcare providers, family members and caregivers. The experience is supervised by a team of healthcare experts who are in the position to monitor the care scenario.

Such integrated care approaches combining pharmacological and a non-pharmacological interventions are novel, cost-effective and attractive. Unfortunately, they are applied only in a handful of facilities despite the obvious benefits to the people living with dementia, the caregivers, and healthcare providers. The reason is that they are not widely known, nor health professionals or leadership have been educated as to their application and benefits. Preliminary outcomes observed in some train cabin simulators installed in nursing homes in France, Italy, and Switzerland have demonstrated that their use substantially improves sleeping disorders, agitation and wandering behaviors of those living with dementia. In addition, improved use of medication can contribute to reducing potential medication errors. In contrast to established and costly pharmacological treatments for the care of people living with dementia, the application of assisted simulation using the train cabin simulator are effective and of low costs. The simulated environment of a virtual trip can also be used to support 'clinical practicums' serving the educational and training needs of healthcare professionals specializing in the care of ageing with behavioural, emotional or cognitive challenges.





PARALLEL SESSION ABSTRACTS

Innovation showcase

Date: Saturday, 28 July 2018

11-002

ASSISTED SIMULATION APPLICATION USING A TRAIN CABIN SIMULATOR: INTEGRATING NON-PHARMACOLOGICAL WITH PHARMACOLOGICAL APPROACHES FOR DEMENTIA CARE

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Innovation showcase

Date: Saturday, 28 July 2018

11-003

THE SOLUTION TO ALZHEIMER'S DISEASE COULD BE A PILLOW RATHER THAN A PILL: RHYTHMIC DEEP BRAIN REACHABLE LOW FIELD MAGNETIC STIMULATION (DMS) IS EXPECTED TO SOLVE THE PROBLEM

Mr. Yunfeng Zheng¹; Yan Zheng² and Xiaomin Wang², (1)Beijing Aldans Biotech Company Ltd, Beijing, China, (2)Key Laboratory for Neurodegenerative Disorders of the Ministry of Education, Capital Medical University, Beijing, China

Abstract:**Introduction:**

Synaptic and neural plasticity damage are important mechanisms of Alzheimer's Disease (AD) development and risk factors. A large body of evidence has shown that stress facilitates hippocampal LTD, impairs LTP, and that chronic stress decreases BDNF levels, impairs hippocampal neurogenesis and causes insomnia and major depressive disorder. These stress-associated diseases increase the incidence of AD. We hypothesised that effective anti-stress intervention would prevent and treat AD and should reverse all these pathological changes through anti-stress. In light of recent failed clinical trials, we focused on the development of non-drug interventions. Specifically, we reviewed the progress of rhythmic deep brain reachable low field magnetic stimulation (DMS).

Results: DMS significantly promotes adult hippocampal neurogenesis and facilitates the development of adult new-born neurons. Remarkably, DMS exerts anti-depressive effects in the learned helplessness mouse model and rescues hippocampal long-term plasticity impaired by restraint stress in rats¹.

1. Clinical research has shown that DMS is effective for MDD. Baseline BDNF in responders was lower than in non-responders, and the change in BDNF at week 2 was the most strongly predicted response².
2. DMS enhances cognitive performances, attenuates A β load, upregulates postsynaptic density protein 95 level, promotes hippocampal long-term potentiation, and partly mitigates neuroinflammatory process in the 5XFAD mouse brain. Intriguingly, the gamma burst magnetic stimulation reverses the aberrant gamma oscillations in the transgenic hippocampal network³.
3. Furthermore, neurogenesis in the hippocampal DG of DMS-treated 5XFAD mice was clearly enhanced. In addition, DMS significantly raised the level of acetylcholine and prevented the increase in acetylcholinesterase activity as well as the decrease in acetyltransferase activity in the hippocampus of 5XFAD mice⁴.
4. A clinical study of 116 cases demonstrated that DMS was effective and safe for the treatment of AD. DMS improves both cognitive and non-cognitive symptoms⁵.

Conclusion: Since DMS outputs a weak strength time varying magnetic field, it can be designed like a pillow for long term home use. We propose Phase III clinical trials for medical device registration.





PARALLEL SESSION ABSTRACTS

Reference:

1. Zhang Y, et al. Deep-brain magnetic stimulation promotes adult hippocampal neurogenesis and alleviates stress-related behaviors in mouse models for neuropsychiatric disorders. *Mol Brain*. 2014 Feb 11;7:11
2. Le Xiao, et al. Rhythmic low-field magnetic stimulation may improve depression by increasing brain-derived neurotrophic factor. *CNS Spectrums*. in press. DOI:10.1017/S1092852917000670
3. J. Zhen et al. Gamma rhythm low field magnetic stimulation alleviates neuropathologic changes and rescues memory and cognitive impairments in a mouse model of Alzheimer's disease. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 3 (2017) 487-497
4. Zhen J, et al. Deep Brain Magnetic Stimulation Promotes Neurogenesis and Restores Cholinergic Activity in a Transgenic Mouse Model of Alzheimer's Disease. *Front. Neural Circuits* (2017)11:48
5. Peng Dan-tao, et al. Clinical study of deep brain magnetic stimulation technique in the treatment of Alzheimer's disease. *Chin J Geriatr*, November 2012, Vol.31, No.11, p929-931





Innovation showcase

Date: Saturday, 28 July 2018

11-004

INTEGRATED COGNITIVE ASSESSMENT (ICA): EMPLOYING ARTIFICIAL INTELLIGENCE FOR EARLIEST DIAGNOSIS OF DEMENTIA

Chris Kalafatis*, Medical Director, Cognetivity, London, United Kingdom

Abstract:

There is currently no available cognitive screening tool that can detect early phenotypical changes prior to the emergence of memory problems and other symptoms of dementia. The vast majority of cognitive tests rely on the patients' capacity to read and write while more educated individuals can often "second-guess" them. The traditional primarily memory-based tests, have been around and widely used for more than 30 years, yet they have failed to offer sensitive early diagnosis tools. Given the decade-long lag between the underlying pathological onset of the disease and memory symptoms in dementia, a memory-based test, even if computerized, will NOT succeed in detecting earliest signs of the disease, ideally at a pre-symptomatic stage.

On the other hand, ICA aims at early detection of cognitive dysfunction by targeting brain functionalities that are affected in the initial stages of the disease, specifically before the onset of memory symptoms. ICA examines the visuo-motor pathway, equipped with an AI engine, it looks for milliseconds of delay detectable in individual's patterns of reaction times due to subtle deteriorations in their neuron-to-neuron signaling.

Studies in the past 20 years reveal that all parts of the visual system may be affected in Alzheimer's Disease, including the optic nerve, retina, lateral geniculate nucleus (LGN) and the visual cortex. Particularly, in early stages of the disease, brain areas associated with the visuo-motor pathway are affected, beginning with the retina, the visual cortex and the motor cortex, so together these represent more effective areas to look for the impact of early stage neurodegeneration as opposed to solely focusing on memory.





PARALLEL SESSION ABSTRACTS

Innovation showcase

Date: Saturday, 28 July 2018

11-005

IT'S NEVER 2 LATE (IN2L) PRESENT THEIR UNIQUE COMBINATION OF ADAPTIVE HARDWARE AND SOFTWARE WHICH DELIVERS A PERSON- CENTERED EXPERIENCE

Debbie Ciesielczyk^{*}, Sales, It's Never 2 Late, Greenwood Village, CO

Abstract:





PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-001

MUSICAL MEMORIES: AN INNOVATIVE TEACHING TOOL FOR GRANDCHILDREN AND THEIR FAMILIES ABOUT THE USE OF INDIVIDUALIZED MUSIC IN PERSONS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIASLinda A. Gerdner PhD,^{*} Self Employed, Burlington, IA**Abstract:**

Persons with Alzheimer's disease and related dementias (ADRD) are often cared for within a multigenerational family. An estimated 26% of family caregivers have children younger than 18 living with them. There is growing recognition that persons with ADRD must be treated within the context of the family, but often the needs of grandchildren are overlooked. Research shows adolescent grandchildren who had a close relationship with a grandparent prior to the onset of ADRD often identify a decline in this relationship following its onset (Celdrán et al. 2010). Behavioral disturbances were identified as a primary reason for this decline. Investigators recommend including grandchildren in informational programs on ADRD and the issues most distressing to them.

Musical Memories is an innovative model for translation of an evidence-based intervention (5th edition) on individualized music into an engaging, realistic picture book to serve as a teaching tool for children and their families. The story introduces the reader to ADRD and the profound effects music can have on those suffering from this debilitating disease. *Musical Memories* reflects the current understanding of ADRD, going beyond the issue of short-term memory loss to address behavioral and psychological symptoms of dementia (BPSD), such as anxiety and agitation with author notes to explain these behaviors.

The story focuses on the relationship between Gabrielle and her grandmother. Gabrielle loves ballet, when her grandmother presents her with tickets to Cinderella, she can hardly wait. But outside the theater after the performance, Gabrielle is frightened and confused by Grandmother's behavior. Gabrielle's mother explains that Grandmother has ADRD. The disease sometimes makes Grandmother forgetful, anxious, and agitated, but Gabrielle soon discovers that through music, she and Grandmother can share memories. One night, Grandmother wakes the family in fear of an intruder, and cannot be calmed. Gabrielle remembers a way to break through Grandmother's fear to help her relax. *Musical Memories* uses a problem solving approach to empower Gabrielle in maintaining a relationship with her grandmother.

This book is designed to empower older children and their families in the use of individualized music by modeling ways it can be used to unveil personhood, promote communication, elicit positive memories, and reduce anxiety. The presentation expands content by explaining common causes of BPSD and basic principles in the use of individualized music, developed by the author, tested by researchers and used by clinicians since the early 1990s. *Musical Memories* is also intended to serve as a valuable resource for health care professionals and educators. A website has been created that includes free downloadable resources for Health Care Professionals, Family Caregivers / Teachers, and Children (<https://gerdnerlinda.wixsite.com/musicalmemories>). Participants will learn the basics of using individualized music for persons with ADRD and may expand their knowledge through the use of free resources.

PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-002

THE MUSIC THAT I LOVE AND REMEMBER: PERSONALIZED MUSIC WITH INTERGENERATION INITIATIVE AND THE AFFECTIVE IMPACT ON ELDERLY WITH DEMENTIA

Jia Yun Chng*; Zhenzhong Hu; Rachael Ho and Melison Phek Leong See, Psychosocial, Apex Harmony Lodge, Singapore, Singapore

Abstract:

Music, as a therapeutic medium, has been used in non-pharmacological approach to enhance the quality of life of people living with dementia, through engendering of positive emotions, reduction of negative emotions and reminiscence. Intergenerational interactions between the elderly and the younger generation have been shown to enhance the quality of life, through enhancement of social and emotional well-being for people living with dementia.

Apex Harmony Lodge, a Dementia Residential Care Home, has embarked on an initiative, Music with Reminiscence, integrating both therapeutic benefits of music and social benefits of intergenerational bonding for its residents. This initiative is part of our Intergenerational Bonding Strand which aims to improve psychosocial well-being of residents, leading to the appreciation of each generation as gifts to one another. Planned as a 3-year collaboration with United World College South East Asia [UWCSEA], Singapore, the main objectives are to enhance quality of life through enhancement of positive emotions and ameliorate negative emotions in residents with moderate stage of dementia, and to facilitate and enhance students' understanding of people living with dementia.

From January 2016 to February 2018, 33 students from UWCSEA and 46 residents were engaged in the weekly program over 38 sessions. Each weekly session typically paired 1-2 students with a resident. Students will interact and accompany residents to listen to their personalised music playlist curated based on the residents' demographical background such as race and age. Students will also aid the reminiscence process by singing with residents, playing percussion instruments or providing a listening ear for residents to share their emotions and thoughts during the session. Observed Emotion Rating Scale is used to assess the affect elicited during the sessions based on observable expressions. Student feedback is gathered to understand their perceptions of elderly with dementia, attitudes on relating to elderly and their key learning.

Findings revealed that elderlies in the program showed positive emotions such as pleasure, general alertness and amelioration of negative emotions such as anger, sadness and anxiety, compared with baseline when the residents are not engaged in the program. Feedback from the students showed that they had gained an enhanced understanding of dementia, and better communication skills with people with dementia. Overall, the results highlight the significant benefits to both generations; well-being of residents which can be enhanced through therapeutic effects of personalized music and intergenerational socialization as well as positive perceptions and deeper understanding of elderly living with dementia by the students.





PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-003

THE CREATIVE USE OF IMAGINATION IN MEMORY: PERSPECTIVES OF A LOST IDENTITY, REDEFINING QUALITY OF LIFE AND THE IMPORTANCE OF NEUROSCIENCES RESEARCH AND CREATIVITY IN ALZHEIMER'S AND RELATED DEMENTIAS

Angel C. Duncan^{*}, Research, Neuropsychiatric Research Center of Southwest Florida, Fort Myers, FL

Abstract:

This session identifies common misconceptions about identity and thought processes in memory for persons living with Alzheimer's disease and related dementias. Going beyond a PET scan and neurocognitive testing scales, case studies and research from around the country of persons with dementia are highlighted by the utilization of expressive arts therapy techniques as a way to examine diagnosis, assessment and treatment interventions from a wellness perspective for persons with Prodromal Mild Cognitive Impairment to late stage Alzheimer's disease. In addition, this session aims to alter the perceptions of how persons living with dementia are perceived by the medical community, with a reliance in lessening psychotropic drug usage. From Alzheimer's clinical research trials to expressive art therapies, the importance of why both pharma and creativity are needed to better enhance quality of life and well-being for those living with neurocognitive impairments, and ways in which to combine both into a best medical model practice.



PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-004

A.L.M.A. ASSOCIATION FIGHT AGAINST ALZHEIMER'S DISEASE OF THE R. ARGENTINA INCLUDES MUSIC IN SEVERAL OF ITS ACTIVITIES FOR PEOPLE WHO LIVE WITH DEMENTIA, CAREGIVERS AND IN A WORKSHOP DESIGNED FOR PRIMARY PREVENTION

Noemí Medina Prof^o, Board, A.L.M.A. Asociación Lucha contra el mal de Alzheimer y alteraciones semejantes, Ciudad Autónoma de Buenos Aires, Argentina and **Marta Jenko Mrs.^a**, Board, A.L.M.A. Asociación Lucha contra el mal de Alzheimer y alteraciones similares, Ciudad Autónoma de Buenos Aires, Argentina

Abstract:

1. "Cognitive Stimulation and Music Therapy Workshops" for people who live diagnosed with some type of dementia. There are in A.L.M.A. 5 annual workshops coordinated by a team integrated of: Psychologists, Music Therapists and Volunteers for a group of no more than 12 participants, persons living with dementia, in each group they enjoy hearing , singing, re-write songs or dance .It is a non-medical and enjoyable way to improve the quality of life for persons through their consistent exposure to music and, whenever appropriate, to dance.
2. "Coffee with A.L.M.A.", is an activity based on the Alzheimer's Café of Dr. Miesen and Dr. Bloom, in which persons living with dementia , caregivers and interested public participate together as guests. Health professionals give information and different musicians close the activity that takes place in a bar in the city once a month. Sing and dance is a very appreciated musical moment in the "Café con A.L.M.A.". It helps to increase confidence, social and communication skills as well as improve self-esteem and over all attentiveness in individuals.
3. The "Primary Prevention Workshop" has been programmed for people interested in adapting their lifestyle and to avoid risk factors and it include Music, Memory and Movement .The 50% of the time in the program is dedicated to harmonizing dance adopted of the national school of Danza Noverazco.



Various aspects of a dance session, such as the music, exercise, and social components of dancing, achieve positive effect in comprehension of benefits to change or modified their lifestyle and promote protective factors.

It is known that Primary Prevention measures are aimed at individuals in the susceptibility stage. It refers to activities or measures, both individual and communal, that are directed at reducing the risk of exposure to a risk factor or health determinant in an individual or the population.

When listening to music, our brain performs auditory motor interactions..

Both language and music have a close relationship with movement, so it is considered that music establishes relationships between different brain functions, relationships that are also considered characteristics of our species. Music would facilitate this type of relationship between different functions, such as emotions, prosody (the tone or melod) of our language, as well as the motor skills associated with the periodicity of movements.



PARALLEL SESSION ABSTRACTS

Undoubtedly, music and movement have gone hand in hand since time immemorial. Music is a multisensory experience, since it involves not only the sense of hearing, but also that of our own movement (proprioception) and that of balance (vestibular system).

Finally, the physical activity involved in dancing and / or taking regular walks, it is highly related to reducing impairment in adult life. (*)

(*) Dr. Cecilia Serrano, Neurologist, Member of the Scientific Committee of A.L.M.A



PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-004

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PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-005

MUSICAL REMINISCENCE THERAPY: GLOBAL SOLUTION FOR IMPROVED DEMENTIA CARE

Mr. Nils Pieter de Mol van Otterloo*, USC Suzanne Dworak-Peck School of Social Work, 2051 La Fremontia St., South Pasadena, CA

Abstract:

In 2016-2017 the author traveled to Cochin, Kerala, India to do research on Musical Reminiscence Therapy for Dementia Care with the Alzheimer's and Related Diseases Society of India (ARDSI) and the Amrita Institute for Medical Sciences. This work proved fruitful developing a social work-based intervention to improve the lives of patients and their families and caregivers.

At the end of 2018 ARDSI will be holding its Diamond Jubilee. The author will share plans to improve awareness of dementia care in India through the development of a fellowship to support the work of ARDSI. The possibilities for improved systems of care through the ARDSI model will be discussed.





PARALLEL SESSION ABSTRACTS

Arts and dementia

Date: Saturday, 28 July 2018

12-006

SWARA (SOUND) FOR CHANGE: A MUSICAL PROGRAM AT A DEMENTIA DAYCARE CENTER TO CHANGE HOW FAMILY MEMBERS VIEW THEIR LOVED ONES WITH DEMENTIA

Nilanjana Maulik^{*}, Alzheimer's and Related Disorders Society of India, Calcutta Chapter, Kolkata, India

Abstract:

According to the Dementia India Report, 2010 the State of West Bengal is expected to experience 100% (or more) change in total number of dementia cases over the next 26 year period. ARDSI (Alzheimer's And Related Disorders Society of India) Calcutta, a non- governmental organization registered in the State since 1999 supports people living with dementia and their family members with a range of services. The daycare center opened in 2008 and runs 6 days a week extending meaningful programs to people living with all types of dementia diagnosed at an outside hospital by their primary care physician or a neurologist and are in their mild to moderate stages. Additionally, support is provided to the family members of those attending the center with monthly meets to share their journey of caregiving.



The viewpoints of family members reported at these meets mostly reflect an experience of complete life change by losing the person they once knew. One particular viewpoint that went like this; "If my father was who he was before this disease, you would see him happily singing all day long with a smile on his face" laid the foundation to experiment with "Swara (Sound) for Change", a musical program. The aim was to minimize the loss experienced by family members.

We choose music among all arts because it is intrinsic to every Indian and also because of its strong ability to unearth a range of emotions.

The program runs for 2 hours a day by daycare center staff and involves playing music ranging from Indian classical to folk or instrumental that speaks about love, happiness, fear or loss. The setting is either at one to one or a group level.

During the sessions, people living with dementia react, respond and engage with the music. These sessions are a sparkling example of their true spirit which is in sheer contrast to the hopelessness of the everyday reality in which they are believed to be living.

Every session is video recorded and then shared with family members in the monthly meets with the goal of empowering them to the fact that their loved ones are still who they knew. A total of 6 meets have been conducted since the start of the program to collect any changed viewpoints. The feedback has indicated to have met the goal of the program. Family members have reported profound connection to the person they once knew.

Keywords: Dementia, Music, Persons living with dementia, Family Members, Daycare center



PARALLEL SESSION ABSTRACTS

National dementia policy: Asia Pacific

Date: Saturday, 28 July 2018

13-001

EFFECTS OF THE DEMENTIA SUPPORTER PROGRAMME - CHANGES IN ATTITUDE AND BEHAVIOUR OF THE WORKERS FOR FINANCIAL SERVICES

Ms. Yumi Shindo*, National Center for Geriatrics and Gerontology, Obu-city, Aichi, Japan and Kentaro Horibe, National Center for Geriatrics and Gerontology, Obu city, Aichi, Japan

Abstract:

Objective: Dementia Supporter Program (DS Program), aiming to understand dementia better and transform the way of thinking, acts, and talks about the dementia, was started in Japan in 2005. Since then, the number of Dementia Supporters has been dramatically increasing and now it reached to 9.8 million in December 2017. Recently, private companies such as banks, life-insurance companies, supermarkets, delivery companies are interested in DS Program in order to meet their corporate social responsibility as well as to deal with their senior customers who are suspected dementia. In this study, we aimed to see effectiveness of DS Program to the private company workers, particularly for workers at financial institutes.

Method: We developed the questionnaire with 15 questions asking what kind of changes in awareness and behavior happened after receiving DS Program. Subjects were selected from the financial institutes of Oita Orange Company, which is the company that more than 50% of its employees received DS Program, in Oita prefecture. The questionnaire was sent to their work place, and the subjects received and answered it, then returned it in the enclosed envelope on an individual base.

Result: 384 employees (male 175, female 208) working for financial institutes answered to the questionnaire. More than 90% of the subjects answered that they learned what dementia was and how to help and deal with the persons with dementia through DS Program. About the changes in awareness and behavior, many subjects answered that they "became to consider my later life strongly agree: 29.3%, agree: 54.2%", and "became to pay close attention to my old parents, relatives and friends (strongly agree: 27.3%, agree: 64.6%)." Also, many of them answered "realized the importance of work with local governments and related agencies working with dementia (strongly agree: 25.8%, agree: 59.1%)," "became to pay attention to my old customers (strongly agree: 22.1%, agree: 70.3%)," and so on. Also, in free answers, many subjects requested to hold DS Program repeatedly.

Conclusion: The result suggested that DS Program is effective to help the financial institute workers to understand dementia better. Also, this result suggests that DS Program helps the workers of financial institutes to change their awareness and behavior to themselves and their loved ones. It is very important to prepare for the later life and DS program is effective to help this. In addition, many of them requested to hold DS Program repeatedly. This might be because they have limited opportunities to learn about dementia.

The main goal of DS Program is to understand dementia better and transform the way of thinking, acts, and talks about the dementia, and this goal is successfully achieved. To see the details of effectiveness, further studies are required.



PARALLEL SESSION ABSTRACTS

National dementia policy: Asia Pacific

Date: Saturday, 28 July 2018

13-002

THE NATIONAL RESPONSIBILITY DECLARATION ON DEMENTIA OF KOREA

Ki Woong Kim¹; Seonjeong Byun¹ and Kiwon Kim², (1)Department of Neuropsychiatry, Seoul National University Bundang Hospital, Seongnam, Korea, Republic of (South), (2)National Institute of Dementia, Seongnam, Korea, Republic of (South)

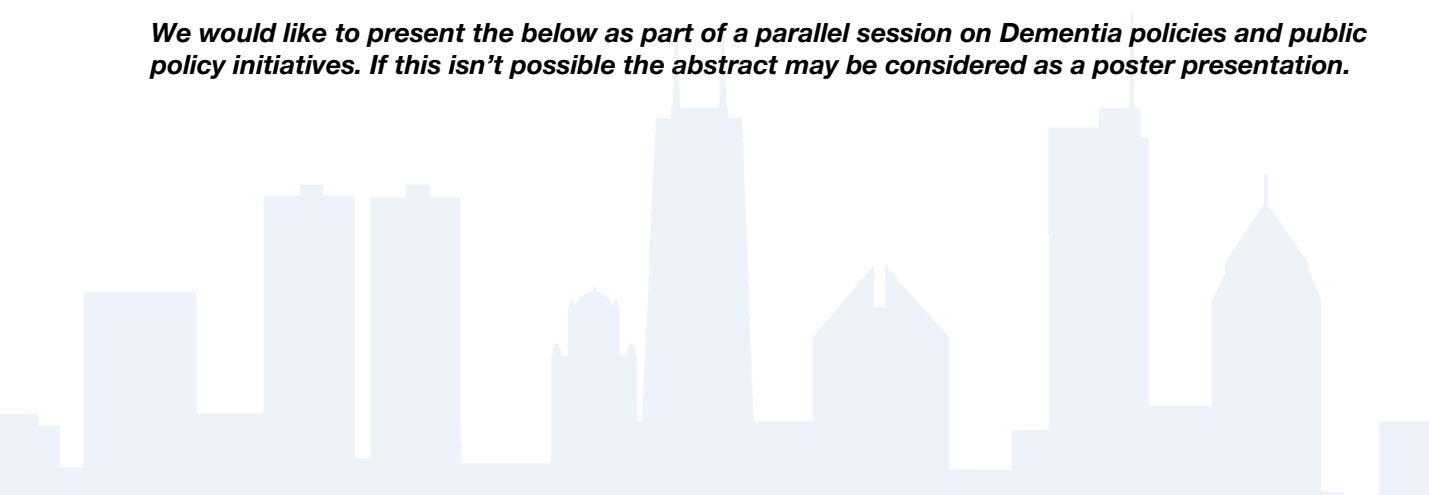
Abstract:

In 2008, Korean government officially placed dementia as a national health priority, announced a war against dementia, and prepared the National Dementia Plan (NDP). The first NDP was prepared in 2008, the second in 2012, and the third in 2016. The Dementia Management Act (DeMA), which was passed the National Assembly in 2011 and enacted in 2012, provides the grounds for carrying out the National Dementia Plans on a stabilized and organized basis. Based on the DeMA and NDPs, the National Dementia Service Delivery System that consists of the National Institute of Dementia in the country, 17 Provincial or Metropolitan Dementia Centers in every province or metropolitan city, and 256 Local Dementia Centers in every district across the country. The Nationwide Dementia Early Detection (NDeED) Service launched in 2008 improved the physical and financial accessibility to early diagnosis of dementia and doubled the diagnostic rate of dementia from about 40% in 2008 to about 80% in 2017. Post-diagnostic services for dementia patients have been continuously strengthened in the same period. As of 2017, over 50% of dementia patients are covered by the National Longterm Care Insurance and Public Elderly Care Service. Since dementia epidemiology in Korea is rapidly transiting from 'low incidence – high mortality' stage to 'high incidence – low mortality' stage, we started putting more emphasis on prevention strategies from the second NDP. Korean citizens are also stepping up together to fight against dementia by joining Dementia Partners. As of 2017, about 0.5 million people completed training as Dementia Partners.

Last year, the president Moon called for the state to take the full responsibility of dementia management. Based on this National Responsibility Declaration on Dementia, the government raised the coverage ratio of the National Health Insurance to cut the out-of-pocket cost for diagnosing and treating dementia patients by half, and will expand the grade of National Longterm Care Insurance so that very mild dementia patients can be covered. The government will spend 160 billion won to build the 200 Local Dementia Centers and 60 billion won to set up the public hospitals specialized for dementia management. The government also established a national committee for preparing the 10-year National Dementia R&D with allocated funding of 1 trillion KRW. Through this new leadership, Korea is preparing for the next decade to make a country more dementia friendly.

Key words: Dementia, Policy, National, Korea

We would like to present the below as part of a parallel session on Dementia policies and public policy initiatives. If this isn't possible the abstract may be considered as a poster presentation.



PARALLEL SESSION ABSTRACTS

National dementia policy: Asia Pacific

Date: Saturday, 28 July 2018

13-003

HOW NON-PROFIT ORGANIZATION CONTRIBUTE TO CHANGE: DEVELOPING NEW TAIWAN DEMENTIA PLAN IN RESPONSE TO THE WORLD HEALTH ORGANIZATION GLOBAL ACTION PLAN

Ms. Li-Yu Tang¹; Te-Jen Lai²; Huey-Jane Lee¹; Tzu-Fen Huang¹; Ee-Ning Chan¹ and Ms. Ya-Chuan Chou¹, (1) Taiwan Alzheimer's Disease Association, Taipei, Taiwan, (2) Chung Shan Medical University, Taichung, Taiwan

Abstract:

To improve the quality of lives of people with dementia, their carers, and families, the Taiwan government issued the national dementia plan in August 2013. Taiwan became the thirteenth country who has a national dementia policy in the world. Furthermore, the Taiwan government announced the 2014-2016 action plan on dementia in September 2014. In response to population ageing and dementia epidemic, the Taiwan government adopted the World Health Organization global action plan on dementia, the opinions of people living with dementia and their families into the draft of the second edition of the Taiwan Dementia Plan by the end of 2017.



The second edition of the Taiwan Dementia Plan covers the period 2018-2025. The policy identifies seven strategies, with action plans, targets, indicators set for each. The strategies are as the following: 1. Recognizing of dementia as a public health priority; 2. Raising dementia awareness and friendliness; 3. Reducing the risk of dementia; 4. Providing timely diagnosis, treatment, care, and support; 5. Providing support services for family carers; 6. Building information system ; and 7. Promoting dementia research and innovation.

Taiwan Alzheimer's Disease Association (TADA) was officially founded in 2002. It is a national non-profit organization. In 2005, TADA became a full member of the Alzheimer's Disease International (ADI). We embarked on a new strategic effort to influence national dementia policy. The three aspects of policy advocacy: partnerships with government, joint efforts of the civil society and connection with the international organization. In the aspect of partnerships with government, Ministry of Health and Welfare (MOHW) commissioned TADA to develop the second edition of the Taiwan Dementia Policy, the establishment of a national-level information system, the system for training general and specialized staff in the health workforce and so on. In the aspect of joint efforts of the civil society, we held four sessions of consensus meetings and civic forums in different area of Taiwan, held a workshop on the dementia policy, conducted the online survey, to collect the suggestions and expectation for the Taiwan dementia policy. About the aspect of connection with the international organization, TADA invited the chair of ADI, Glenn Rees and the chair of Dementia Alliance International, Kate Swaffer to Taiwan. They are very helpful to us in promoting our national dementia policy. On 25 August 2017, the President of Taiwan, Tsai Ing-Wen has an interview with Glenn and representatives from the TADA. The president committed to issue a new Taiwan dementia plan. Kate help us to raise the awareness of the human rights of people living with dementia in Taiwan. This became the task of the Control Yuan that will continue to track the government's effort to protect the rights of people with dementia.

In the future, Taiwan Ministry of Health and Welfare will hold the supervision and evaluation meetings on dementia plan regularly. TADA will do our best to advocate for people living with dementia and their carers, and work with the Taiwan government, the civil society and ADI.

Keywords: national dementia plan, dementia policy, non-profit organization



PARALLEL SESSION ABSTRACTS

National dementia policy: Asia Pacific

Date: Saturday, 28 July 2018

13-004

NEW TAIPEI CITY MODEL

Chi-Hung Lin*, Department of Health New Taipei City, New Taipei City Government, New Taipei City, Taiwan and Shih Naichia, New Taipei City Government, 新北市, Taiwan

Abstract:

Dementia is a complicated disease requires continuous, holistic and integrated care. It is necessary to construct a complete care network between governments with connected community and healthcare facilities.

New Taipei City dementia support model provides community empowerment for finding early cases of dementia, linking the medical institutions to confirm and delay the degradation of cognitive function.

The model also provides appropriate assistance and support by hospital with the telephone follow-up or interview. Hospitals offer the referral of resources such as care tips, resource links and caring services to maintain the independence of cases and reduce the pressure on family care. This is the found of NTPC dementia caring network.





PARALLEL SESSION ABSTRACTS

National dementia policy: Asia Pacific

Date: Saturday, 28 July 2018

13-005

AN OVERVIEW ON THE KOREAN DEMENTIA REGISTRY (KODER)

Seonjeong Byun^{*1}; Jiwon Ju²; Ki Woong Kim¹ and You Jeong Kim², (1)Department of Neuropsychiatry, Seoul National University Bundang Hospital, Seongnam, Korea, Republic of (South), (2)National Institute of Dementia, Seongnam, Korea, Republic of (South)

Abstract:

The Korean Dementia Registry (KoDeR) was established in December 2017 by the National Institute of Dementia (NID) to provide Korean people with optimal services for preventing, diagnosing and managing dementia, to support the effective operation of local and regional dementia centers across the nation, and to monitor the outputs and outcomes of the national dementia strategies.

The KoDeR is an internet based quality registry that includes information about the prevention activities, diagnostic work-up, medical treatment and care data for dementia. Either non-demented individuals who need prevention programs or early diagnosis or dementia patients and their caregivers who need postdiagnostic services can be registered to the KoDeR. The KoDeR is in sync with the systems of the NID and the National Police Agency to provide integrated services for caregivers and missing dementia patients, and will be synchronized with the National Health Insurance Service system and the National Social Security Information system in the future.

The KoDeR has three main user groups; the employees of the local dementia centers for providing services, those of the provincial or metropolitan dementia centers for supporting and monitoring local dementia centers in each region, and those of the NID for supporting dementia centers, monitoring the progress, outputs and outcomes of the national dementia strategies, and maintaining the system.

In the near future, the KoDeR will become a key herb to establish the Korean Dementia Observatory, and a platform to improve the national guidelines for dementia prevention, diagnosis and management.

Key words: Dementia, Dementia Registry, Dementia Care Centers





PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-001

COHORT STUDY ON FACTORS ASSOCIATED WITH THE (NON)-UTILISATION OF FORMAL CARE SERVICES IN EUROPE: FINDINGS OF THE EUROPEAN ACTIFCARE STUDY

Liselot Kerpershoek^{*}, Department of Neuropsychology and Psychiatry, Maastricht University, Maastricht, Netherlands

Abstract:

Objective: The Actifcare cohort study investigated service use, needs and quality of life of community-dwelling people with mild to moderate dementia and their informal carers. Actifcare aims to increase our understanding why people with dementia and their carers use, or fail to use formal care services. In addition, the potential inequity of access to and delivery of services was investigated.

Method: A prospective one-year cohort study was conducted with 451 dyads (person with dementia and their informal carer) in eight European countries (The Netherlands, Germany, United Kingdom, Sweden, Norway, Ireland, Portugal and Italy). Follow-up measurements took place at 6 and 12 months after baseline. Logistic regressions were carried out to investigate baseline predictors of formal care use at follow-up, and to assess potential inequity in access. In-depth interviews were conducted after 12 months to explore barriers, facilitators and experiences regarding access to care

Result: Predictors for formal care use were a lower score on instrumental- and daily activities of life questionnaires, the person with dementia living alone, having a higher educated informal carer, and the informal carer visiting a support group. Older and higher educated people with dementia and younger carers found access to home personal care easier, and lower educated carers were more likely to be admitted sooner. These findings indicate inequity in access to care. Qualitative results showed among others that there is a lack of information about available services, and that having a key contact person is crucial. Furthermore needs should be taken into account when finding the right type of care, and attitudes towards care usually shift as disease severity increases.

Conclusion: These results help to define best-practice strategies for access to formal care in dementia across Europe, enabling people with dementia and their carers to receive the right amount and intensity of formal care when and where needed, and to increase their quality of life.





PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-002

A LOCAL MODEL FOR BRAIN HEALTH EDUCATION, ENGAGEMENT AND SUPPORT FOR COMMUNITY-DWELLING ADULTS

Krystal L. Culler*, Lifelong Learning, Menorah Park | Global Brain Health Institute, 27100 Cedar Road, OH

Abstract:

Engagement in cognitive based interactions and meaningful activities may help offset the symptom progression among individuals with mild cognitive impairment (MCI), different types of dementia and Alzheimer's disease. Epidemiological evidence continues to support the theory that mentally active lifestyles are associated with lower incidence of cognitive decline and dementia. As part of the charitable outreach of our non-profit organization, Menorah Park created the first non-pharmacological, non-hospital based center for brain health located on a senior living campus in the United States. Created upon four pillars of brain health – Cognitive Fitness, Emotional Wellness, Social Well Being, and Personal Health – this community-based “model” for brain health provides a comprehensive, integrated approach to helping community members, professionals and campus residents understand, implement and improve brain health throughout Northeast Ohio and nationally.

An informal community needs assessment demonstrated a need to serve individuals who are waiting to receive a memory related diagnosis and/or are part of the worried well population in Northeast Ohio. The center completes a continuum of care to allow individuals with dementia, as well as, aging adults with brain health concerns to be supported in the community. The center emphasizes a psychosocial “model” of brain health through extensive low-cost programming that includes: education, engagement and support for those concerned about memory and thinking skills, including those diagnosed and not diagnosed with brain health issues.

To date, the center has had impact over 5,000 adults aged 32-104 and serves over 1,500 adults annually. Nearly 82% of participants are active aging adults, 15% of participants report some type of dementia diagnosis and/or brain health concern (Alzheimer's disease, vascular dementia, MCI, post-chemotherapy brain, and post-stroke rehabilitation) and about 3% of participants report other mental health concerns (depression, anxiety and the psychiatric symptoms). Mixed-methods have been utilized to evaluate the program on an ongoing basis. In this presentation, participant engagement data and program evaluation surveys from the first two operational years will be reviewed. Qualitative outcomes indicated that participants felt engagement in the program was beneficial to their personal health and reported the brain-based educational classes were pertinent to brain health. Next steps for program evaluation will also be explored.

The center aims to lead the way to translate the latest evidence-based brain health research into everyday practices for adults and serve as a national and international “model” for non-pharmacological, non-hospital based brain health centers. The array of complimentary programs and services offered at the center aligns with the goals of national and worldwide brain health initiatives; thus, creating a community-based model for brain health programs and services. Current efforts of the center focus on raising awareness about brain health and wellness, providing educational information, and helping aging adults, including individuals with dementia, translate current scientific research in order to enhance their daily lives and ultimately strengthen their brain health and wellness.



PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-003

OPTIMISING INDEPENDENCE OF OLDER PERSONS WITH COGNITIVE AND FUNCTIONAL DECLINE - INTERDISCIPLINARY HOME-BASED REABLEMENT PROGRAM (I-HARP): A PARALLEL-GROUP PILOT RCT

Yun-Hee Jeon¹; Luisa Krein²; Judy Simpson³; Lee-Fay Low³; Lindy Clemson³; Sharon Naismith³; Sarah Szanton⁴; Peter Gonski⁵; Richard Norman⁶; Laura Gitlin⁷; Loren Mowszowski³ and Henry Brodaty⁸, (1)Sydney Nursing School, University of Sydney, Sydney, NSW, Australia, (2)Sydney Nursing School, University of Sydney, Sydney, Australia, (3)University of Sydney, Sydney, Australia, (4)Johns Hopkins University, Baltimore, MD, (5) Sutherland Hospital, Sutherland, Australia, (6)Curtin University, Perth, Australia, (7)Johns Hopkins University, Baltimore, (8)Centre for Healthy Brain Ageing, University of New South Wales, Sydney, Australia

Abstract:

Objective: A major gap exists in providing care to support and maintain functional and social independence of older people with dementia at home. Our interdisciplinary Home-bAsed Reablement Program (I-HARP) integrates evidence-based strategies and cognitive rehabilitation into a dementia-specific person-centred, time limited, home-based, interdisciplinary rehabilitation package. We conducted a parallel-group pilot RCT of I-HARP with community-dwelling people with amnesic mild cognitive impairment (MCI) and mild to moderate stages of dementia to test feasibility and potential effects of I-HARP in Sydney, Australia.

Method: I-HARP involved up to 10 home visits by Occupational Therapist, Registered Nurse, plus additional options of other allied-health support, tailored to the individual client's needs; up to A\$1000 home modification/ assistive devices; and individual carer support, all provided over 4 months. Assessments of the client's daily activities, mobility and health-related quality of life, as well as caregiver burden and quality of life were conducted at baseline, 4 months (post-intervention) and 12 months from baseline.

Result: Eighteen dyads were randomized equally into the two groups using a computer program. Clients were: aged 64-91 years, with MMSE ranging between 16-30, ten were female, nine had Alzheimer's disease, seven with other types of dementia, and two had amnesic MCI. At 4 months, the intervention group showed a 1.83-point improvement in functional independence (ADL/IADL) using the Disability Assessment for Dementia (DAD) while the control group (usual care) declined by 4.22 points. The difference of 6.06 (SD 9.95) displayed a clinically meaningful effect size of 0.61. At 12 months, the intervention group showed a decline in functional independence of 6.63 while the control group had a decline of 12.06, a difference of 5.43 (SD 16.90), giving an effect size of 0.32. Three of the control group clients were placed into care homes while all of the intervention clients were still living at home at 12 months. Interviews with carers and field notes suggested a strong endorsement of I-HARP, and carers' observation of the person becoming more independent and socially engaged as a result of I-HARP.

Conclusion: The results point to the benefit of an interdisciplinary team as having the maximum impact. Our pilot trial demonstrated that I-HARP enhances the functioning of older people with dementia, and their improved mobility, independence, and both self-perceived and observed wellbeing and confidence that enables their ability to live at home for significantly longer. An improved larger scale trial of I-HARP is currently underway.



PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-004

THE WORK OF “DEMENTIA INTERPRETERS” IN AN EMERGING MODEL OF CARE FOR PEOPLE WITH DEMENTIA (PWD)

Kelley A Horton*, Dementia Connections Coalition, LLC, Littleton, CO and Dr. Mary L. Radnofsky Ph.D, Once Human, Forever Human, Alexandria, VA

Abstract:

When people are newly diagnosed with dementia, they struggle to understand the next steps after a drawn-out journey of pursuing an “official” diagnosis of dementia. It can take months, often years, for a physician to finally identify a specific dementia type. However, once the diagnosis is given, doctors usually either recommend “prescribed disengagement” (Swaffer, 2014), or a “wait-and-see until there is a change” approach. “Moving from a ‘person’ to the ‘label of a person with dementia’ overnight and not having support. No one to talk to about having dementia. All the support is directed towards carers. There was no one to talk to about my future.” (Bryden, 2016). This is a common problem, with no one to walk alongside and explain the path they are now on, navigate the bumps and turns, and encourage them if they falter.

To address this problem, we propose an emerging model of dementia care that involves a “dementia interpreter” whose role is to ensure that the lived experiences of the PwD, their personal history, along with their defined current hopes and goals, are accurately and clearly represented at the time of diagnosis, and that any information transmitted to them is also understood.

The value of the PwD interpreter, who is neither a care partner nor a medical professional, is also to encourage the PwD to use their own voice. I have been a certified Dementia Consultant and certified Personal Historian for over ten years, using mediation as a means to facilitate communication between the person with dementia and caregivers or doctors, especially when there are transitions in care, or a change of condition I’m able to interpret the doctor’s words for the newly-diagnosed PwD, and I use various techniques I will demonstrate to get the PwD perspective communicated back to the doctor or caregiver.

The interpreter also facilitates communication of perceived expectations and helps PwD articulate new goals throughout the decision-making process, such as how and where they choose to live today and in the future.

This model is built on the foundation that, as people age, they utilize their past and resulting resilience to achieve well-being. My experience as a mediator is that when PwD initially hear the words, “You have dementia,” they don’t hear or comprehend much after that, even when they suspected the diagnosis. They generally don’t ask additional questions and need time to vent and/or process the news, as well as talk about their past, present and future, with all the emotions attached. This is easier with an interested third party. They tend to open up to someone who has some knowledge of their type of dementia and won’t judge them or become emotional. They come to understand that I am on their side and I can summarize their needs or concerns. This information ensures that PwD, carers, and doctors all understand what’s important to the person with dementia, so that care can revolve around those wishes and needs, and not what’s most convenient for the caregiver. In turn, it re-enforces to the PwD that they are still in control and have a voice in their care.

This session presents examples of the model by an experienced mediator, a PwD, and a volunteer from the audience to compare and demonstrate the effectiveness of different approaches in communication and the participation of a dementia interpreter. There will be an opportunity to discuss cases and scenarios proposed by PwD. Support materials will also be provided.



PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-005

ALZHEIMER'S ASSOCIATION DEMENTIA CARE PRACTICE RECOMMENDATIONS FOR LONG-TERM CARE AND COMMUNITY BASED PROFESSIONALS

Sam Fazio^{*}, Care & Support, Alzheimer's Association, Chicago, IL and **Mr. Doug Pace**^{*}, Care & Support, Alzheimer's Association, Washington, DC

Abstract:

In order to ensure that people living with Alzheimer's or related dementia are receiving high quality care that is based on the most up to date evidence, the Alzheimer's Association has updated our quality care guidelines. The updated peer-reviewed evidence based Dementia Care Practice Recommendations were released in a special supplement of the February 2018 edition of *The Gerontologist*. The topic areas are person-centered care, detection and diagnosis, assessment and care planning, medical management, information, education and support, ongoing care, staffing, therapeutic environment and safety, and transitions and coordination of care.

This session will provide an overview of the recommendations and discuss how they can be used to increase the quality of care and quality of life for people with Alzheimer's and related dementias.

Discussion questions -

Why is person-centered care important for people with Alzheimer's and related dementias?

What are some promising practices around good dementia care?

Why is detection and diagnosis of Alzheimer's disease important for people experiencing memory loss and their families?

By the end of this presentation attendees will understand the importance of evidence-based recommendations for health care professionals across the continuum of long-term services and supports for people with Alzheimer's and related dementias.

By the end of this presentation attendees will gain an understanding of the each of the topic areas of the updated dementia care practice recommendations and how they can be applied in all settings in long-term services and supports for use by health care professionals

By the end of the presentation attendees will increase their knowledge about the latest facts, figures, current research initiatives and programs of Alzheimer's disease and related dementias.



PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-005

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PARALLEL SESSION ABSTRACTS

Models of care

Date: Saturday, 28 July 2018

14-006

CLUSTERED 'HOMELIKE' MODELS OF RESIDENTIAL AGED CARE ARE ASSOCIATED WITH FEWER HOSPITALISATIONS, BETTER QUALITY OF LIFE AND SIMILAR COSTS: AN AUSTRALIAN CROSS-SECTIONAL STUDY

Suzanne Marie Dyer*, Rehabilitation, Aged and Extended Care, Flinders University; NHMRC Cognitive Decline Partnership Centre, Bedford Park, SA, Australia; Enwu Liu, Australian Catholic University, Melbourne, Australia; Emmanuel Gnanamanickam, Rehabilitation, Aged and Extended Care, Flinders University, NHMRC Cognitive Decline Partnership Centre, Bedford Park, Australia; Julie Ratcliffe Prof, Institute for Choice, University of South Australia, Adelaide, Australia; Rachel Milte Dr, Rehabilitation, Aged and Extended Care, Flinders University, NHMRC Cognitive Decline Partnership Centre, University of South Australia, Adelaide, Australia; Tiffany Easton, Rehabilitation, Aged and Extended Care, Flinders University, NHMRC Cognitive Decline Partnership Centre, Bedford Park, Australia and Maria Crotty, Flinders University, NHMRC Cognitive Decline Partnership Centre, Adelaide, Australia

Abstract:

Objective: To examine the consequences in terms of resident centred outcomes and costs of living in a 'homelike' clustered model of residential aged care in comparison to a standard Australian model.

Method: A cross-sectional study with 12-month retrospective linked health service usage data. 17 residential care facilities in 4 Australian states providing either 'homelike' cluster or standard model of care. Inclusion criteria were those residing in care for 12 months or longer, not in immediate palliative care, including those with cognitive impairment, having a family member willing to participate on their behalf if necessary. 901 residents were eligible and 541 consented (24% self-consent, 76% proxy). Main outcomes were quality of life, quality of care and hospitalisations.

Result: All residents in a clustered 'homelike' model of care had either a dementia diagnosis or a PAS-Cog of five or more indicative of cognitive impairment in comparison to 79% of those in standard care facilities. After adjustments, individuals residing in clustered 'homelike' models of care had better quality of life (EQ5D5L difference 0.107, 95%CI 0.028 - 0.186), better consumer-rated quality of care (Consumer Choice Index - 6 Dimension (CCI-6D) difference 0.138, 95%CI 0.073 - 0.203), lower hospitalisation rates (rate ratio [RaR] difference = 0.318, 95% CI 0.128 - 0.786) and lower ED presentation rates (RaR difference = 0.273, 95%CI 0.142 - 0.526), in comparison to those residing in a standard care facility. The rate of general practitioner consultations did not differ (RaR difference = 1.31, 95%CI 0.752- 2.28). There was a predicted total (health and residential care) annual cost saving of approximately AU\$14,000 (2016, 16% of total) per person associated with the clustered model of care, after adjustments, which was statistically significant considering costs to government.

Conclusion: Clustered domestic models of residential care are associated with better quality of life and fewer hospitalisations with no increment in whole of system costs. Provision of care in clustered domestic models may be a financially beneficial approach for government and society and these models should be further explored. More information is needed on financial, attitudinal and regulatory barriers to expansion of clustered housing approaches in residential aged care.

PARALLEL SESSION ABSTRACTS

Prevention (Risk reduction and risk factors)

Date: Saturday, 28 July 2018

15-001

DIETARY PATTERNS AND BETA-AMYLOID DEPOSITION IN AGEING AUSTRALIAN WOMEN

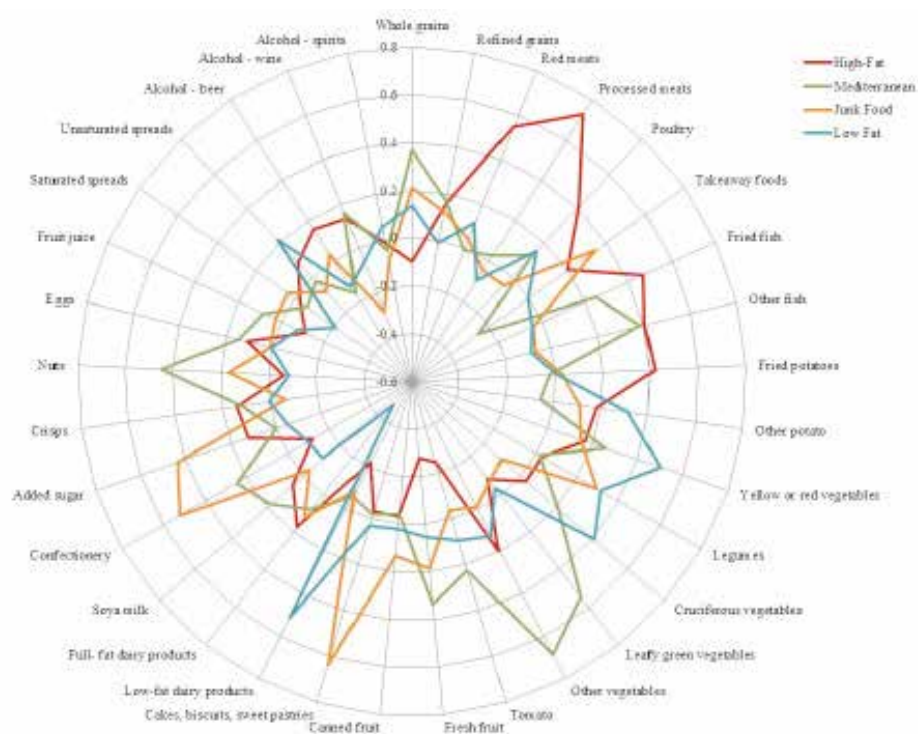
Edward A Hill^{1,2}; Alicia Goodwill^{1,3} and Cassandra Szoek^{1,3}, (1)Institute for Health & Ageing, Melbourne, Australia, (2)Centre for Medical Research, The Royal Melbourne Hospital, Melbourne, VIC, Australia, (3)Centre for Medical Research, The Royal Melbourne Hospital, Melbourne, Australia

Abstract:

Objective: Diet may play a major role in the Alzheimer's disease (AD) pathology and offer great potential for non-pharmacological prevention. Epidemiological evidence reveals an association between diet and AD incidence and prevalence, yet few studies have investigated this relationship with respect to the hallmark protein implicated in AD; beta amyloid ($A\beta$). The objective of this study was to investigate dietary patterns using an a priori approach and their associations with $A\beta$ deposition in healthy ageing Australian women

Method: Participants were sought from the 2012 follow-up of the Women's Health Ageing Project

(WHAP), an epidemiologically sourced prospective study of healthy ageing Australian women. Participants completed a validated food frequency questionnaire reflecting intakes over the past 12 months and daily intakes of foods and nutrients were estimated by the Cancer Council of Victoria. All food items were reported in grams per day and placed into 33 food groups defined a priori. Dietary patterns were extrapolated from food groupings using iterated principal factor analysis with oblique varimax rotation. $A\beta$ deposition was measured via in vivo F-18 Florbetaben positron emission tomography (PET) scanning and standard uptake value ratios (SUVR) were generated by normalizing regional SUVRs. PET SUVR displayed a positive skew that was rectified using 1/square transformation therefore results should be interpreted as inverse coefficient derivatives. Complete data was available for 115 participants. Generalized linear models (GLM) were used to assess associations between $A\beta$ deposition and dietary patterns scores, adjusted for age and education in years, body mass index (BMI), energy intake (kJ/day), cognition (The Consortium to Establish a Registry for Alzheimer's Disease [CERAD] Savings) and binary presence of the apolipoprotein epsilon-4 allele (APOE ϵ 4) allele). All analyses were performed in STATA v14.





Result: In this study WHAP participants were, on average; aged 70 years (± 2.63 SD), had 13 years of education (± 3.57 SD), a BMI of 28kg/m^2 (± 5.46 SD) and an energy intake of 5161 kJ/day (± 1679.03 SD). Four dietary patterns were identified: High-Fat, Mediterranean, Junk Food and Low-Fat. Factor loadings (Figure 1) indicated the unhealthy Junk-Food pattern was characterized by high consumption of takeaway foods, confectionery and cakes, biscuits and sweet pastries. The Mediterranean type diet was characterized by a high consumption of fruits, vegetables, nuts and fish. High-Fat loaded heavily on meats and fried foods, whilst Low-Fat loaded heavily on low-fat dairy products and vegetables. Adherence to the Junk-Food diet was a significant predictor of $A\beta$ deposition ($\beta = .10$, $p < .05$) as was binary presence of the APOE $\epsilon 4$ allele ($\beta = .11$, $p < .05$). The three other dietary patterns were not associated with $A\beta$ deposition. Age, education, BMI, energy intake and cognition (CERAD Savings) were also not significantly associated with $A\beta$ deposition.

Conclusion: Only adherence to the unhealthy Junk-Food dietary pattern was a significant predictor of $A\beta$ deposition in the fully adjusted model. This study highlights the potential of diet to influence neurodegenerative disease and is the first, to our knowledge, to demonstrate that an unhealthy diet confers similar effect size on $A\beta$ deposition as presence of the APOE $\epsilon 4$ allele.





PARALLEL SESSION ABSTRACTS

Prevention (Risk reduction and risk factors)

Date: Saturday, 28 July 2018

15-002

BOTH EXECUTIVE DYSFUNCTION AND PHYSICAL INACTIVITY INFLUENCE PHYSICAL DECLINE IN OLDER ADULTS ACROSS THE COGNITIVE SPECTRUM

Morag E Taylor^{*1,2,3}; Sirinun Boripuntakul⁴; Barbara Toson⁵; Jacqueline CT Close^{2,5}; Stephen R Lord⁵; Nicole A Kochan^{6,7}; Perminder S Sachdev^{6,7,8}; Henry Brodaty^{8,9} and Kim Delbaere⁵, (1)Falls, Balance and Injury Research Centre, Neuroscience Research Australia, Sydney, NSW, Australia, (2)Prince of Wales Clinical School, Medicine, University of New South Wales, Sydney, Australia, (3)Cognitive Decline Partnership Centre, Sydney Medical School, The University of Sydney, Sydney, Australia, (4)Department of Physical Therapy, Chiang Mai University, Chiang Mai, Thailand, (5)Falls, Balance and Injury Research Centre, Neuroscience Research Australia, Sydney, Australia, (6)Centre for Healthy Brain Ageing, School of Psychiatry, Medicine, University of New South Wales, Sydney, Australia, (7)Neuropsychiatric Institute, Prince of Wales Hospital, Randwick, Australia, (8)Dementia Centre for Research Collaboration, School of Psychiatry, Medicine, University of New South Wales, Sydney, Australia, (9)Centre for Healthy Brain Ageing (CHeBA) and Dementia Centre for Research Collaboration (DCRC), School of Psychiatry, Medicine, UNSW Sydney, Sydney, Australia

Abstract:

Objectives: Individuals with mild cognitive impairment (MCI) and dementia have physical impairments and increased fall risk when compared to their cognitively intact peers. However, there is limited literature examining physical decline in samples that include individuals across the cognitive spectrum and how cognitive function, physical activity and falls influence decline in this population. We investigated physical decline over 1-year in a cohort of older people across the cognitive spectrum and examined which factors (i.e., neuropsychological domains and/or physical activity) were associated with physical decline and how falls during follow-up affected this relationship. We also investigated the relationship between falls and physical decline over 1-year.

Methods: Physical function was assessed using the Physiological Profile Assessment (PPA) in 593 participants (cognitively normal [CN]: $n=342$, mild cognitive impairment [MCI]: $n=77$, dementia: $n=174$) at baseline and in 490 participants available for reassessment 1-year later. Neuropsychological performance and physical activity (PA) were assessed at baseline. Falls were recorded prospectively for 1-year using monthly calendars and telephone calls, as well as carer assistance for participants with dementia.

Results: Median baseline PPA scores for CN, MCI and dementia groups were 0.41 ($IQR=-0.09-1.02$), 0.66 ($IQR=-0.06-1.15$) and 2.37 ($IQR=0.93-3.78$) respectively. All baseline neuropsychological domains and PA were significantly associated with baseline PPA. There were significant interaction terms (Time \times Cognitive Group, Global Cognition, Processing Speed, Executive Function and PA) in the models investigating PPA decline. In multivariate analysis the Time \times Executive Function and PA interaction terms were significant, indicating that participants with poorer baseline executive function and reduced PA demonstrated greater physical decline when compared to individuals with better executive function and PA respectively while controlling for age, education, medication use and falls. With falls during follow-up categorized as zero falls, one fall and 2+ falls, each unit increase in PPA score over 1-year was associated with a 29%, OR 1.29, 95%CI [1.12, 1.48], increased odds of being in the next faller status category compared to the previous faller status category or categories.

Conclusions: Having MCI or dementia is associated with greater physical decline over 1-year compared to cognitively normal older people. Physical inactivity and executive dysfunction were independently associated with physical decline in this population, which included older adults with MCI and dementia. Both factors are potentially amenable to interventions e.g. exercise. Physical decline was associated with an increased risk of falling during follow-up. However, both decline and falls were occurring over the same timeframe and each could influence the other.



PARALLEL SESSION ABSTRACTS

Prevention (Risk reduction and risk factors)

Date: Saturday, 28 July 2018

15-003

DIETARY PATTERN, HYPERTENSION AND COGNITIVE FUNCTION IN AN OLDER POPULATION: RESULTS FROM A TEN-YEAR LONGITUDINAL SURVEY

Xiaoyue Xu Dr¹; Deborah Parker Prof²; Zumin Shi Prof³; Julie Byles Prof⁴; John Hall Prof⁵ and Louise Hickman Prof¹, (1)University of Technology Sydney, Sydney, Australia, (2)Faculty of Health, University of Technology Sydney, Sydney, NSW, Australia, (3)The University of Adelaide, Adelaide, Australia, (4)University of Newcastle, Newcastle, Australia, (5)University of New South Wales, Sydney, Australia

Abstract:

Objective: Research into the association between diet and cognitive function among older Chinese is extremely scarce. The aims of this study were: 1) to examine the association between dietary pattern and cognitive function; and 2) to test whether there is an interaction between dietary pattern and hypertension in relation to cognitive function for older Chinese people.

Method: We analysed data from the China Health and Nutrition (CHNS) survey, which is an ongoing open cohort of nine waves (1989-2011). The survey used a multistage random-cluster sampling process to select samples from nine provinces in China. Dietary data has been collected since 1991, and cognitive function interview data were collected between 1997 and 2006. Dietary assessment is based on each participant's 24 hour-recall, with information collected over three consecutive days. The CHNS adopted the cognitive screening items from part of the Telephone Interview for Cognitive Status-modified, which has been used in the Chinese population. We analysed ten years of data for 7,769 older persons (aged ≥ 55 years). Exploratory factor analysis was used to identify dietary patterns using the standard principal component analysis method. Cognitive function measures include global cognitive scores and verbal memory scores. Linear mixed models were used to investigate the longitudinal association between dietary patterns, hypertension and cognitive function after adjusted for socio-demographic and health behaviour factors.

Result: There were total 7,769 participants involved in the analysis: with N=1,402 in 1997, N=1,608 in 2000, N=2,198 in 2004 and N=2,559 in 2006. Over time, there was significant decrease for verbal memory scores. Two dietary patterns were identified from factor analysis, named 'Rice-based' and 'Protein-rich' dietary pattern. 'Rice-based' dietary pattern was loaded heavily on rice, pork and fish, and inversely on wheat and whole grain. Protein-rich dietary pattern was characterised by high intake of milk, soy milk and eggs, and inversely on rice and salted vegetables. Protein-rich dietary pattern was significantly associated with higher global scores and verbal memory scores. However, the association was only found among older people with a higher education level. In the adjusted model, compared with participants in lowest quartile of protein-rich dietary pattern, participants in the highest quartile had 0.95 significantly higher global scores ($p=0.02$), and 1.63 verbal memory scores ($p<0.001$). No association was found between Rice-based dietary pattern and cognitive function. There is no interaction was found between hypertension and dietary pattern impacting on cognitive health, but we found hypertension to be an independent factor which is significantly associated with cognitive function. Participants with hypertension had 0.21 (95% CI: -0.39; -0.02) lower verbal memory scores than those with no hypertension.

Conclusion: We found a significant role of a protein-rich dietary pattern in slowing the process of the cognitive decline among a Chinese older population, particularly for people with high education levels. In addition, hypertension to be an independent risk factor for cognitive decline. Identification of older populations with low education level who had hypertension should be targeted in intervention studies to maintain their cognitive health.



PARALLEL SESSION ABSTRACTS

Prevention (Risk reduction and risk factors)

Date: Saturday, 28 July 2018

15-004

MOTIVATION AND WILLINGNESS TO CHANGE LIFESTYLE FOR DEMENTIA RISK REDUCTION: PRELIMINARY RESULTS FROM A NATIONAL UK SURVEY WITH PEOPLE AGED 50+

Deborah Oliveira¹; Aimee Aubeeluck²; Lauren Yates Dr¹; Eef Hogervorst³; **Sarang Kim**^{*4} and Martin Orrell Prof¹, (1)Division of Psychiatry and Applied Psychology, University of Nottingham, Nottingham, United Kingdom, (2) School of Health Sciences, University of Nottingham, Nottingham, United Kingdom, (3)School of Sport, Exercise and Health Sciences, Loughborough University, Loughborough, United Kingdom, (4)Research School of Population Health, Australian National University, Canberra, Australia

Abstract:

Objective: There is increasing evidence of the association between lifestyle factors and dementia risk and it is important to know about peoples' levels of motivation and willingness to change their lifestyle to potentially reduce their dementia risk. This presentation will show preliminary findings of an ongoing study aimed at investigating motivation and willingness to change lifestyle for potential dementia risk reduction in people aged 50+ in the UK.

Method: A national online survey was carried out with a non-probabilistic sample of 1,988 people aged 50+ without dementia (2017-2018). The variables of interest were: demographics; current lifestyle/health status; motivation to change lifestyle (MCLHB-DRR scale); and willingness to change lifestyle (1-5 Likert questions based on the current lifestyle, e.g. if smoker, it was asked how much he/she would be willing to stop smoking). Descriptive and associative statistics for gender and age (chi-square) were used.

Result: Participants were mostly females (72%), mean age 61 (SD=9; range=50-91), white British (96%), with excellent or very good self-rated health (61%). Approximately 4% smoked and of these 43% said they were willing to stop; 74% drank alcohol at least 2x/month and 74% were willing to reduce; 77% were physically active and 73% were willing to improve; 90% reported healthy diets and 84% were willing to improve; 81% were willing to lose weight. Women were more willing to lose weight, stop smoking, reduce alcohol intake and have a healthier diet. Older people were less willing to reduce alcohol intake or adopt a healthier diet than middle-aged adults. Overall, positive motivation levels were found in the total sample. Women had better cues to action, perceived severity and perceived susceptibility. Perceived benefits and cues to action decreased with age. Perceived barriers increased with age.

Conclusion: Males and older adults were less motivated and less willing to change lifestyle to potentially reduce dementia risk. This survey investigated generally healthy people who are mostly willing and motivated to reduce their potential dementia risk. We are currently completing the recruitment of participants and carrying out further analyses. Implications to research and clinical practice will be discussed in relation to current policies and literature on dementia risk reduction.



PARALLEL SESSION ABSTRACTS

Prevention (Risk reduction and risk factors)

Date: Saturday, 28 July 2018

15-005

MAINTAIN YOUR BRAIN - AN INTERNET-BASED RANDOMISED CONTROLLED TRIAL TO PREVENT COGNITIVE DECLINE

Henry Brodaty¹; Gavin Andrews²; Kaarin J Anstey³; Maria Fiatarone Singh⁴; Louisa Jorm⁵; Nicola Lautenschlager⁶; Anthony Maeder⁷; John McNeil⁸; Perminder S Sachdev⁹; Megan Heffernan¹ and Michael Valenzuela¹⁰, (1)Centre for Healthy Brain Ageing, University of New South Wales, Sydney, Australia, (2)St Vincent's Psychiatry, University of New South Wales, Sydney, Australia, (3)Neuroscience Research Australia, University of New South Wales, Sydney, Australia, (4)Faculty of Health Sciences and Sydney Medical School, The University of Sydney, Sydney NSW, Australia, (5)Centre for Big Data, UNSW, Sydney, Australia, (6)Academic Unit for Psychiatry of Old Age, University of Melbourne, Melbourne, Australia, (7)Digital Health Systems, Flinders University, Adelaide, Australia, (8)School of Public Health & Preventive Medicine, Monash University, Melbourne, Australia, (9)Neuropsychiatric Institute, Prince of Wales Hospital, Randwick, Australia, (10)Brain and Mind Centre, University of Sydney, Camperdown, Australia

Abstract:

Objective: To devise and evaluate an internet based intervention targeting risk factors for dementia designed to prevent or delay cognitive decline and dementia.

Method: A sample of 16,000 persons aged 55-75 years will be drawn from the 45 and Up Study, a population based study of 1-in-10 persons who were aged 45 or more in 2006-09 and living in New South Wales, Australia. Persons will be invited to participate if they have at least two identified risk factors amenable to intervention, a computer and internet access and willingness to be involved. Intervention participants are allocated to receive online coaching in up to four 10-week modules in the first year tailored to their risk profile – cognitive training, physical activity, nutrition and peace of mind (targeting depression, mindfulness, stress management or insomnia) – followed by quarterly boosters over the three years of follow-up. All assessments (baseline and annual) are conducted online. The control group receive information without online coaching from up to four of the intervention modules based on their risk profile.

Results: The IT platform has been constructed and a pilot completed. From 2000 invitations, 425 persons consented to participate, and 245 completed screening questionnaires. Of the 245, 103 were aged 55-64 and 142 were 65-75. Overall mean age was 65.9 (SD 5.1) and 54% were female. Risk factor rates varied from 24% related to mood, to 78% for cognitive activity, 90% for physical activity and 94% for nutrition. Many participants reported lack of strength training (70%), low adherence to a Mediterranean Diet (88%) and low levels of cognitive activity in late life (59%). All participants were eligible for at least one intervention module and 90% were eligible for two. Recruitment for the main trial starts in April 2018.

Conclusion: There is a vast potential for intervention in the general population. Participants were prepared to engage with an online health intervention broadly aimed at these risk factors.



PARALLEL SESSION ABSTRACTS

Prevention (Risk reduction and risk factors)

Date: Saturday, 28 July 2018

15-006

CONNECTING THE DOTS PART 2 - THE DEMENTIA WELLNESS PROJECT: A CULTURALLY APPROPRIATE LIFESTYLE INTERVENTION FOR AFRICAN AMERICAN ELDERS AT RISK FOR DEMENTIA

Gina Green-Harris MBA¹; Michelle Corbett MPH²; Carrie Stehman MA²; Stephanie Houston MBA³; Teresa Skora NP⁴; Carla Wright MD⁴; Nia Norris MA¹ and Dorothy Edwards PhD⁵, (1)Wisconsin Alzheimer's Institute, Milwaukee, WI, (2)Center for Urban Population Health University of Wisconsin School of Medicine & Public Health, Milwaukee, WI, (3)UW Madison, Wisconsin Alzheimer's Institute, Milwaukee, WI, (4)Milwaukee Health Services, Inc., Milwaukee, WI, (5)Wisconsin Alzheimer's Disease Research Center, Madison, WI

Abstract:

The prevalence of Alzheimer's disease and other dementias among older African Americans is roughly double than that among non-Hispanic whites and is significantly higher than that among Hispanics. African Americans are also at greater risk for vascular and chronic conditions such as hypertension and diabetes which a growing body of evidence suggests increases risk for cognitive impairment. Research also indicates that many African American cultural norms do not support healthy eating and physical activity, placing African Americans at increased risk for poor vascular health and consequently, poor cognitive health. The Dementia Wellness Project, a community-academic partnership between Milwaukee Health Services, Inc., the Wisconsin Alzheimer's Institute, and the Center for Urban Population Health, aimed to address these disparities through the development of a culturally appropriate lifestyle intervention that would 1) increase awareness and knowledge of brain health and the relationship between diet and physical activity, vascular risks, and brain health, and 2) increase knowledge of and capacity to engage in health protective behaviors. The 5-session group intervention, Healthy Body/Healthy Mind Connection (HBHMC), combined lecture, discussion, demonstration and practice, games, movement, role playing, reflection, and goal setting. Co-facilitated by a community-based nurse practitioner and an outreach specialist, HBHMC was delivered in 7 senior housing buildings and 1 senior center in Milwaukee, WI between July 2015 and October 2017 to a total of 86 participants of whom three-quarters were African-American age 55+. Qualitative and quantitative process and outcome evaluation data was collected at baseline, post-session, immediate post-intervention, one-month, and three-months post intervention. These data indicate that HBHMC is acceptable to members of the project's priority population as evidenced by the overall high satisfaction ratings across intervention sites. Behavioral changes between baseline and three-month follow-up include an increase in mean fruit and vegetable consumption. Biometric changes at three-month follow-up include decreases in mean Body Mass Index, systolic blood pressure, total cholesterol, and A1c hemoglobin. The mean score for self-reported quality of life improved significantly between baseline and three-month follow-up. This presentation will 1) describe the development and implementation of HBHMC; 2) describe the process and outcome evaluation; 3) share results and key findings; and 4) offer recommendations for the replication of this promising intervention.



Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

16-001

DEVELOPING NEW TECHNOLOGIES FOR DEMENTIA

Janus Kremer Dr^{*}; Pablo Bagnati and Ricardo Allegri, University of Cordoba, Córdoba, Andalusia, Spain

Abstract:

Objective: The aim of this project is to review the state of the art of technologies for persons with dementia regarding issues on development, usability, effectiveness and cost-effectiveness, deployment, and ethics in 3 fields of application of technologies:

- (1) support with managing everyday life,
- (2) support with participating in pleasurable and meaningful activities, and
- (3) support with dementia health and social care provision.

This project also attempts to identify gaps in the evidence and challenges for future research.

Method: We review the literature available.

Literature searches were conducted on usability, effectiveness and cost-effectiveness, and ethics using PubMed, specific dementia databases with no time limit.

We also used searching engines such as Google and Yahoo.

As well, we inquired Amazon and eBay stores.

Selection criteria in our selected technology fields were reviews in English and Spanish for community-dwelling persons with dementia.

Regarding deployment issues, searches were done in Health Technology Assessment databases.

Result: According to our results, persons with dementia want to be included in the development of technologies; there is little research on the usability of assistive technologies; various benefits are reported but are mainly based on low-quality studies; barriers to deployment of technologies in dementia care were identified, and ethical issues were raised by researchers but often not studied.

Many challenges remain such as including the target group more often in development, performing more high-quality studies on usability and effectiveness and cost-effectiveness, creating and having access to high-quality datasets on existing technologies to enable adequate deployment of technologies in dementia care, and ensuring that ethical issues are considered an important topic for researchers to include in their evaluation of assistive technologies.

Conclusion: Based on these findings, various actions are recommended for development, usability, effectiveness and cost-effectiveness, deployment, and ethics of assistive and health technologies worldwide.

These include avoiding replication of technology development that is unhelpful or ineffective and focusing on how technologies succeed in addressing individual needs of persons with dementia.

Furthermore, it is suggested to include these recommendations in national and international calls for funding and assistive technology research programs.

Finally, practitioners, policy makers, care insurers, and care providers should work together with technology enterprises and researchers to prepare strategies for the implementation of assistive technologies in different care settings.

This may help future generations of persons with dementia to utilize available and affordable technologies and, ultimately, to benefit from them.



PARALLEL SESSION ABSTRACTS

Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

16-002

THE EFFECTIVENESS OF INLIFE: AN INNOVATIVE ONLINE PLATFORM TO SUPPORT THE CAREGIVER SOCIAL NETWORK OF PEOPLE WITH DEMENTIA

Alieske E.H. Dam^{*}; Martin P.J. van Boxtel; Frans Verhey and Marjolein E de Vugt, Maastricht University, Maastricht, Netherlands

Abstract:

Objective: During the caregiving trajectory of persons with dementia (PwDs), informal caregivers are at risk of facing social isolation, burden and of experiencing a high threshold to either seek or provide support [1]. Therefore, an online social support intervention entitled 'Inlife' was developed and launched in the Netherlands. Inlife is a personalized online social platform offering a range of functionalities to facilitate positive interaction and support within caregiver networks of PwDs.

Method: A mixed method, single blind, randomized controlled study with 96 primary caregivers of PwDs was conducted [2]. Caregivers were randomly assigned to either the Inlife intervention or a waiting-list control group, receiving care as usual. After the 16-week study-period the control group obtained access to Inlife. Ten caregivers from the intervention group were interviewed to evaluate the process characteristics (i.e. implementation and intervention quality). Primary qualitative outcome measures included feelings of caregiver competence and perceived social support. Secondary outcome measures included received support, loneliness, psychological complaints and quality of life.

Result: The qualitative results showed that Inlife facilitated empowerment, openness, involvement, and efficient care-organisation. Adherence was not optimal for all users. Determinants of Inlife use were identified on the level of the Inlife innovation, the users, and the socio-political context. Based on *preliminary* qualitative analysis no significant differences were found on the primary and secondary outcome measures.

Conclusion: Inlife was qualitatively evaluated as a promising instrument for efficient central care coordination and mutual involvement. On a quantitative level no significant effects were demonstrated. However, the qualitative results suggest that online support tools might be promising to improve openness and awareness of support needs in caregiver networks of PwDs. Furthermore, qualitative research methods next to conventional quantitative research methods might have an added value in the evaluation of dynamic caregiver interventions using e-health.

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PARALLEL SESSION ABSTRACTS

Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

16-003

PREDICTION OF ALZHEIMER'S DISEASE DEMENTIA WITH DEEP LEARNING

Anantha V Santhanam*; Mark H Ereth; Jamison Feramisco and Ayin Vala, Foundation for Precision Medicine, Arlington, TX

Abstract:

The transformative impact of machine learning and Artificial Intelligence has not been fully realized in medicine and especially personalized medicine. Every day we see examples of the impact of machine learning and artificial intelligence in transportation, information technology, finance, and other sectors. However, the transformative impact has not been fully realized in medicine and especially personalized medicine. Computing has become very powerful and analytics algorithms have become smart enough to spot patterns in patient characteristics and treatments to provide discovery. By introducing more data-driven investigation we can take into account individual variability in medicine intake, lifestyle, and genetic factors for each person and use the power of big data and artificial intelligence to treat challenging diseases. Our study is focused on a deep learning model developed on 70,000 records from Alzheimer's disease patients that helps to identify patients at high risk of dementia, using medication regimens, historical diagnosis, risk factors, and care programs. We will also highlight the ways we have used cloud platforms to develop more intensive algorithms, manipulate data in faster ways, and the ability to visualize actionable data for Alzheimer's disease researchers. Results obtained demonstrate a successful proof-of-principle demonstration of the use of deep learning to predict Alzheimer's disease dementia earlier. Current efforts are underway to increase the sensitivity of the current deep learning model and incorporate other relevant clinical variables to increase this window of prediction.





PARALLEL SESSION ABSTRACTS

Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

16-004

THE KOREAN NATIONAL MOBILE PLATFORM FOR SUPPORTING DEMENTIA MANAGEMENT; “CHECK DEMENTIA”

YunHye Jo¹; Seonjeong Byun²; Ki Woong Kim² and **Riyoung Na³**, (1)Strategic Business Dept., National Institute of Dementia, Seongnam, Korea, Republic of (South), (2)Department of Neuropsychiatry, Seoul National University Bundang Hospital, Seongnam, Korea, Republic of (South), (3)National Institute of Dementia, Seongnam-si, Korea, Republic of (South)

Abstract:

In Korea, the number of people with dementia (PWD) is double every 17 years. At the moment, one out of four Koreans have a chance to get dementia before they die. In other words, all Koreans who get married have a chance to care a dementia patient among their parents or parents-in-law. Although the services for supporting Koreans to cope with dementia are rapidly expanding, many Koreans still have difficulties in finding and using them. Delivering the dementia-related services is as important as developing them.

The **Check Dementia**, an mobile application working on both IOS and Android, was developed in 2013 by the Korean National Institute of Dementia to assist Korean people with active prevention, early diagnosis and smart care of dementia and efficient track of the appropriate services. It provides three key services; self-screening for dementia, searching for public services for dementia, and care-supporting tools for caregivers. The self-screening tool can relay the users to the National Dementia Early Detection (NDeED) Program provided by Public Health Centers across the nation. The dementia service navigation tool provides a list of public services that are eligible and optimized to each user. The care-supporting tools include a location-based service to prevent PWD from missing and to help lost PWD get back home early and safely. In addition, the care-supporting tools provide a care diary and a medication alarm.

Since its release in 2013, **Check Dementia** has been downloaded about 200,000 times, and won the Smart App Award Korea in 2014. Now **Check Dementia** is used by the staffs of all Dementia Counselling Centers in South Korea, being recognized nationally for its practicality.

Key words: Dementia, Check Dementia, National Institute of Dementia, Dementia Counselling Centers





PARALLEL SESSION ABSTRACTS

Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

16-005

THE DIGITAL FUTURE OF DEMENTIA CARE: HOW ALZHEIMER SCOTLAND IS USING THE DEMENTIA CIRCLE MODEL TO DRIVE BEST PRACTICE IN DIGITAL INNOVATION AND TO INFORM THE DEVELOPMENT OF NEW PERSON CENTRED TECHNOLOGY PRODUCTS AND SERVICES

Nicola M Cooper Ms; Tommy Petillo Mr; **Gillian Anderson*** and Charlotte Swarbrick Ms, Development, Alzheimer Scotland, Edinburgh, United Kingdom

Abstract:

This presentation aims to give an overview of the Dementia Circle protocols and methodologies. These have coalesced over the course of the past six years to become a system that we apply to environments and products, and now to technology and digital services.

We will demonstrate Dementia Circle's pioneering approach to evidencing the potential of digital as a person centred, cost effective solution for people living with dementia (PLWD).

dementiacircle.org provides an online platform for the exchange of ideas and feedback on products and services tried and tested by PLWD. This forum gives unbiased, peer authored reviews and an insight into what PLWD and their carers are using and finding useful in the real world.

Today Dementia Circle is a way of looking through the lens of the user and a means of testing change. The testing protocols and methodologies have been applied to products, services, environments and digital technologies to drive improvements, innovation, new learning and knowledge, and most importantly positive outcomes for PLWD.

Health and Social Care leadership in Scotland and the imminent publication of a new Digital Health and Social Care Strategy 2017-22 point to technology being integrated into all aspects of health and social care, resulting in significant challenges and also opportunities for PLWD.

We are seeing a growth in the use of everyday consumer technology e.g. Alexa Voice Assistant and an interest in Virtual Reality experiences. We have written the FIRST EVER dementia specific "Skill" for Alexa and are looking at ways to partner developers like Waracle* in Voice first technology innovations for PLWD.

To support the workforce with this cultural shift we facilitated learning days with over 500 practitioners from health and social care, housing, voluntary sector and partner organizations across Scotland. Our 2017 cohort are now helping families to consider technology as part of their care bundle.

Alzheimer Scotland is investing in service users and rethinking what it means to be a smart patient when everyone is a consumer of digital health and care. Through Dementia Circle we are amplifying the voices of those living with dementia to design what the dementia care of today and tomorrow will look like.

Digital Health and Social Care Strategy 2017-22 ScotGov (Draft)

Technology has the potential to reshape Scotland's health and social care, providing better services and a better working environment for professionals.

As a citizen of Scotland: "I have access to the digital information, tools and services I need to help maintain and improve my health and wellbeing."

Scotland's National Dementia Strategy (2017 – 2020)

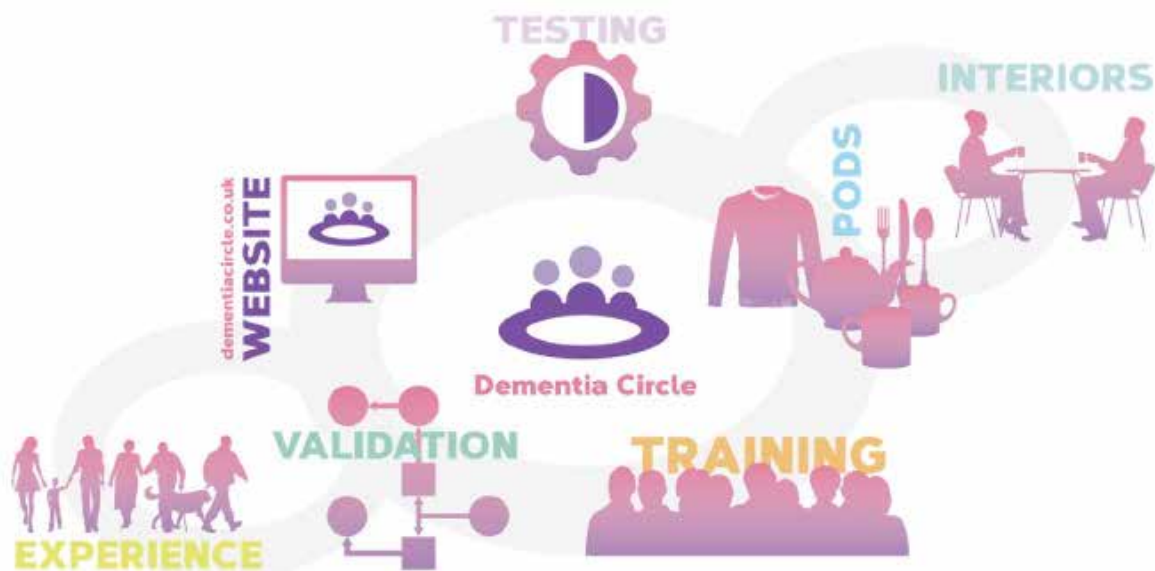
PARALLEL SESSION ABSTRACTS

COMMITMENT 11: We will implement the Technology Charter for People in Scotland with Dementia, ensuring that everyone with a diagnosis of dementia and those who care for them are aware of, and have access to, a range of proven technologies to enable people living with dementia to live safely and independently. We will continue to explore innovative ways in which technology can be used and adapted for people living with dementia.

*waracle.com

“The increasing use of mobile devices, improved distribution of diagnostic health services and the drive for cost effective services are just some of the reasons digital health and care, is becoming a big deal.”

Waracle is a Scottish Company and one of the UK's leading mobile app development, IoT and digital consulting companies, with partners globally.





PARALLEL SESSION ABSTRACTS

Technology, innovation and entrepreneurship

Date: Saturday, 28 July 2018

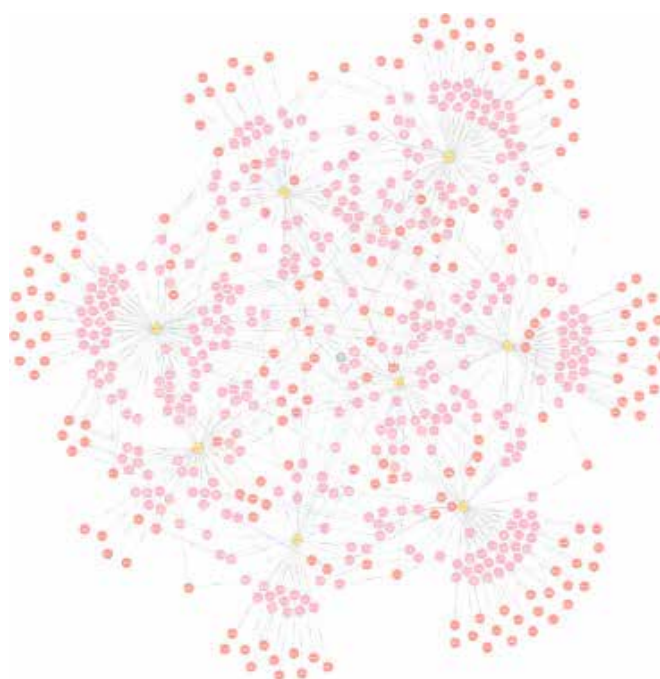
16-006

INNOVATIVE SOFTWARE PLATFORM FOR TARGETING DYSREGULATED EPIGENETIC PATHWAYS AND IDENTIFYING NOVEL THERAPEUTIC APPROACHES IN ALZHEIMER'S DISEASE: A COMPREHENSIVE APPROACH

Loretta R Anderson*, Mental Health, Johns Hopkins Bloomberg School of Public Health, Reisterstown, MD and Andrew A Pollack, Epigenetic Data Sciences, Reisterstown, MD

Abstract:

The Alzheimer's disease (AD) drug development market has a 99.6% failure rate (Cummings, J., et al, 2014). Additionally, in 2017, the cost to American society to care for those with Alzheimer's was estimated to be \$259 billion (2017 Alzheimer's Association Fact Sheet). This lack of progress in both disease-modifying and symptomatic treatments for AD coupled with the unsustainable growing costs of the disease dictates the necessity for creating innovative approaches to drug discovery. Technological advances have been made over the last decade, particularly with respect to data science tools owing to the exponential increase of data to be processed and analyzed. These tools allow for new insights to be leveraged that were hitherto not visible. This paper discusses a new technological advancement in the search for novel therapeutic approaches using data science and epigenetics to bring new hope to Alzheimer's.



We developed a software suite to aid in the full-cycle process of ingesting raw data, providing research tools for identification of epigenetically dysregulated genes and pathways and analysis of all known chemical interactions affecting these pathways in Alzheimer's disease. Using graph theory, natural language processing, artificial intelligence, and machine learning, we applied these tools to identify chemical and supplement interactions to counteract dysregulated pathways in AD. The knowledge that is constructed allows us to optimize our output based on factors including gene-gene, gene-chemical, and chemical-protein interactions.

We constructed a proprietary data science platform which generates optimal treatment plans for Alzheimer's disease based on dysregulated epigenetic pathways and individualized genetic risk factors. The output generated is optimized against an entire pathway, allowing for higher levels of downstream success in the targeted gene.

With the continued failure of clinical trials to bring an effective drug to market, a novel interdisciplinary approach grounded in data science will enhance the discovery phase of clinical trials. In addition to drug targets, the software suite can identify scientifically proven over the counter products, offering those living with Alzheimer's and their caregivers' additional options, and decreasing the time needed for patients to access effective therapies.

PARALLEL SESSION ABSTRACTS

Consumer experience, lifestyle and nutrition

Date: Saturday, 28 July 2018

17-001

A VISUAL JOURNEY THROUGH THE AUSTRALIAN HEALTHCARE SYSTEM AS EXPERIENCED BY PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS

Janna Anneke Fitzgerald¹; Joanne M Curry²; Angelique Olde Meierink³ and **Ashley Cully³**, (1)Griffith University, Gold Coast, QLD, Australia, (2)DXC Technology, Melbourne, Australia, (3) Griffith University, Gold Coast, Australia

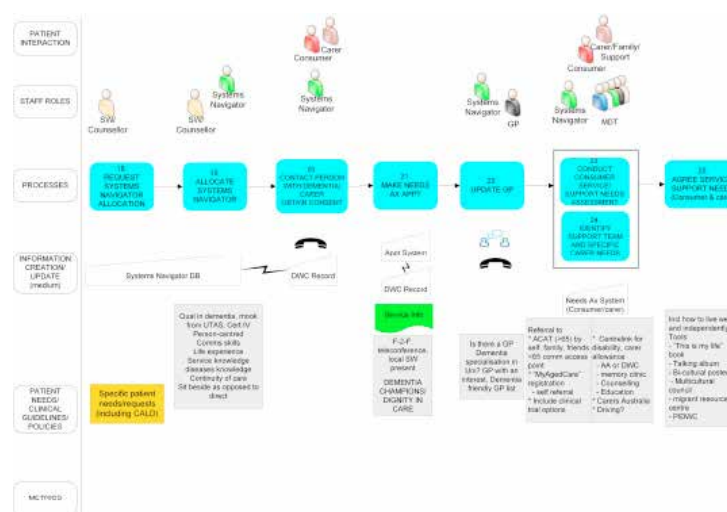
Abstract:

Objective: To better understand the individual journeys of people with dementia and their carers through the Australian healthcare system. Whilst care pathways for people living with dementia have been in existence for some time, little research has focussed on the impact of these interventions on the real-life experiences of the consumer. Further, we sought to discover opportunities for improvement of the care pathway as suggested by people with dementia and their carers.

Method: Stories were collected from 25 people with dementia and carers, resulting in the creation of 18 visual storyboards. Opportunities for improvements were elicited and synthesised into an additional visualisation – an “ideal” journey model. Data was collected through five face-to-face workshops, each lasting two days, across 3 states of Australia.

Result: Several issues were identified in the “current state”, including an extensive delay between recognition of symptoms and diagnosis. Once diagnosed, experiences of treatment and support were diverse with little coordination of care or thought for the impact on the consumer. Knowledge and clarity of available services was difficult to obtain, and clinical pathways were largely unknown. Much of the carer support received was reactive rather than proactive. An “ideal” journey model showed opportunities for improvement.

Conclusion: With the expected increase in dementia-related illnesses, a better understanding of the impact and healthcare pathway of dementia is essential to the design and delivery of future public and private health services. The consumer voice is vital in driving future research and allocation of effort.





PARALLEL SESSION ABSTRACTS

Consumer experience, lifestyle and nutrition

Date: Saturday, 28 July 2018

17-002

HAVING A SAY – PEOPLE WITH MEMORY RELATED DISEASES AS CUSTOMERS IN FINNISH SOCIAL- AND HEALTHCARE SERVICES

Kirsti Kuustera* and Mari Luonsinen, Alzheimer Society of Finland, Helsinki, Finland

Abstract:

Objective: The social- and healthcare services in Finland, one of the Nordic welfare countries, are being remodelled towards a more efficient, egalitarian and person-centred care. As the population is aging, the elderly are seen as a group that needs lots of services and can be potentially impactful customer segment. However, in the public discourse, the diagnosis of dementia seems often to be a reason to move a person to the outer edge of his/her care. This exploratory, small scale qualitative study aims to look at the experiences of people with memory related diseases and their family-members as customers in social- and healthcare services.

Method: The data was collected from 6 people with diagnosis and 7 family members in two phases. 1) Group discussion about experiences as customer in social- and healthcare services 2) Structured interviews on themes raising from the group interview were conducted with four people with memory related diseases. The interviewees were actively involved with the work of the Alzheimer Society of Finland and had mainly experiences from the services needed at the early stages of dementia. In the analysis, we looked at the experiences and discourses deriving from the data.

Result: *Being a customer.* The social- and healthcare services played a small part in the lives of the interviewees. They seemed to be happy to follow the guidance of professionals and did not require unique services. The family members with a longer experience of living alongised someone having a memory related disease, highlighted the importance of peer support in order to find out more about available service options. The people with memory related disease were mentally prepared for a future where they might not have much influence over their care and support.

Coordinated services. The most rewarding experiences were when the person with memory related disease or family members did not need to actively seek for help but the support was offered by a familiar professional, such as a memory/dementia coordinator. The interviewees emphasized the need for tailored services and wide array of options to choose from.

Role of family-members. The interviewees saw inclusion of family members in the care planning as positive and supporting, especially when the social- and healthcare services are often relatively fragmented and complex. In the daily life the family-members were crucial enablers of a “normal” life. However, the interviewees valued their own independence and demanded to be heard in their case.

Conclusion: It is estimated that in Finland 40 % of the patients receiving medical care at home and 75 % of elderly care home inhabitants have a diagnosis of dementia. According to prior studies the possibilities to participate to the planning of your own care diminishes as the disease progresses. Thus people with memory related disease should be actively involved in choosing their services and new practical tools to enhance customer/patient involvement should be developed in cooperation with the people with memory related diseases.



PARALLEL SESSION ABSTRACTS

Consumer experience, lifestyle and nutrition

Date: Saturday, 28 July 2018

17-003

THE NHMRC PARTNERSHIP CENTRE FOR DEALING WITH COGNITIVE AND RELATED FUNCTIONAL DECLINE IN OLDER PEOPLE: AN AUSTRALIAN MODEL FOR PUBLIC INVOLVEMENT IN DEMENTIA RESEARCH

Jane F Thompson¹; Joan Jackman²; Shannon McDermott²; Alexandra Kitching² and Sue Kurrle², (1)Member of the Public, Canberra, Australia, (2)NHMRC CDPC, Sydney, Australia

Abstract:

Increasingly, the benefits of actively involving the people who will be directly affected by research (also referred to, among other terms, as consumers, patients and the public or, simply, the public) in that research are being recognised. In Australia, its peak funding body for medical research, the National Health and Medical Research Council (NHMRC), provides guidance in its 2016 *Statement on Consumer and Community Involvement in Health and Medical Research*. However, we are in a relatively embryonic, but developing, state in terms of the practical application of the principles of public involvement in research compared with for example, our UK counterparts where the organisation INVOLVE provides leadership and guidance. Public involvement in research is not yet as embedded in Australia's research culture. And, nationally, dementia research lags behind in comparison with, for example, cancer research.

Nonetheless, there are pockets of excellence in practice. This presentation will describe one such model, the NHMRC *Partnership Centre Dealing with Cognitive and Related Functional Decline in Older People* (CDPC) established in 2013. A first of its kind in Australia, the CDPC has thoughtfully integrated people with dementia, carers and former carers into almost all aspects of its research and knowledge translation activities. This is relatively rare in the Australian research context. The majority of these so-called "consumers" are volunteers.

The vision of the CDPC is to improve the lives of people living with cognitive decline or dementia through the co-creation and dissemination of knowledge that changes policy, systems and practice. The Centre involves industry, researchers, and "consumers" working together in partnership. People affected by dementia are involved in every CDPC research activity, in its Executive Committee, its Scientific Sub-Committee, and they participate actively in all CDPC events. They are involved in a variety of functions when working with research projects. For example, they provide feedback on research questions, research instruments and outputs, and also assist in translating research findings. These activities are coordinated by a "Consumer Enabling Subunit" led by a part time paid "Consumer Investigator" funded by Dementia Australia.

Importantly, "consumers" have been invited to contribute to the development of proposed projects from the conceptual stage through to final approval. They have brought a varied mix of personal and professional backgrounds to the CDPC, and, above all they have brought a passion and determination to be actively involved, with other research team members, to make a difference to the lives of people with dementia and the people who share their lives.

An internal evaluation conducted in 2014 identified six essential elements to working successfully in partnership with "consumers": Commitment – to shared goals; Research cultures – defining expectations and roles; Problem solving – through communication, compromise and support; Resourcing – volunteers, support and inclusivity; Communication – targeted, frequent, respectful; and, Trust – through respect and generosity.

These six key elements will help to build a culture that is inclusive and welcoming of public involvement in research and may be a model for other organisations to follow.



PARALLEL SESSION ABSTRACTS

Consumer experience, lifestyle and nutrition

Date: Saturday, 28 July 2018

17-004

BARRIERS TO OPTIMISING NUTRITIONAL STATUS IN RESIDENTS LIVING WITH DEMENTIA: RATIONALE FOR DEVELOPMENT OF THE MEANINGFUL ENGAGEMENT IN NUTRITIONAL UNDERSTANDING (MENU) PROJECT

Emma J Lea¹; Lyn Goldberg²; Andrea Price²; Fran McInerney²; Kathleen V Doherty²; Elizabeth Beattie³ and Liz Isenring⁴, (1)Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, TAS, Australia, (2)Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, Australia, (3)School of Nursing, Queensland University of Technology, Brisbane, Australia, (4)Faculty of Health Sciences and Medicine, Bond University, Robina, Australia

Abstract:

Objective: Dementia increases the risk of malnutrition. International studies show malnutrition rates among people living with dementia in nursing homes are high. Australia is no exception, with half of all nursing home residents malnourished. This presentation will outline findings from an Australian pilot study which led to the design of a new intervention to facilitate Meaningful Engagement in Nutritional Understanding (MENU) and improve care for nursing home residents living with dementia.

Method: A pilot ethnographic case study was conducted to examine food and nutrition care practices in one nursing home. Data were collected via a document audit, review of residents' files, observations of 7 residents living with dementia, and interviews with 7 family and 11 staff members. Interview data were subjected to thematic analysis and triangulated with other data sources.

Result: Five major barriers to provision of best evidence resident-centred nutrition care were identified - 1. Body Mass Index not measured, 2. limited staff knowledge about the relationship between nutrition and key clinical health indicators, 3. attentive but ineffective care practices (e.g. prompts to eat, drink positioning), 4. lack of meal choice, and 5. eating being viewed as a task rather than an enjoyable social activity. Interviews with staff showed they have many ideas for nutrition care practice improvements, such as the need for a pleasurable and non-distracting eating environment, but lack the support required to initiate many of these changes. Staff education and providing an opportunity for staff from various roles to 'brainstorm' ideas were recognised by interviewed staff as a way forward.

Conclusion: The pilot study identified a range of barriers which decrease the ability of residents living with dementia to participate in their own care and prevent a best evidence approach to their nutritional care. The ideas raised by staff for improvements to care suggest the importance of a participatory approach to overcome such barriers and implement change. These findings, together with what is known from the literature, have been used to design the MENU multi-component nutrition support intervention. The MENU approach proposes that nutrition care will be improved by the adoption of a participatory, whole-of-organisation, multi-component intervention. A unique component is the identification and implementation of best evidence care specifically suited to each nursing home. The intervention involves residents, family members, management, and staff across all roles collaboratively selecting, implementing and evaluating best evidence nutrition care strategies for people living with dementia, tailored to the needs and conditions of each nursing home. Strategies will take into account that good nutrition is more than nutritional status and the nutritional content of food provided, encompassing factors that improve quality of life, such as a pleasant eating environment and person-centred care practices. A quasi-experimental mixed methods approach will be used to trial MENU in two Australian nursing homes, including impact on staff and family awareness of best nutrition care and support for residents living with dementia, and malnutrition prevalence. If the trial is successful, implementing MENU may enhance staff capacity to practice best evidence care, reduce nutrition-related ill health and optimise quality of life for nursing home residents living with dementia.



PARALLEL SESSION ABSTRACTS

Consumer experience, lifestyle and nutrition

Date: Saturday, 28 July 2018

17-005

A SYSTEMATIC REVIEW AND META-ANALYSIS OF THE ASSOCIATION BETWEEN SOCIAL ENGAGEMENT, LONELINESS, AND RISK OF DEMENTIA

Ross Penninkilampi, Dementia Centre for Research Collaboration (DCRC), School of Psychiatry, Medicine, UNSW Sydney, Sydney NSW, Australia; **Anne-Nicole Casey**, Centre for Healthy Brain Ageing (CHeBA), School of Psychiatry, Medicine, UNSW Sydney, Sydney NSW, Australia; Maria Fiatarone Singh, Faculty of Health Sciences and Sydney Medical School, The University of Sydney, Sydney NSW, Australia and Henry Brodaty, Centre for Healthy Brain Ageing (CHeBA) and Dementia Centre for Research Collaboration (DCRC), School of Psychiatry, Medicine, UNSW Sydney, Sydney, Australia

Abstract:

Objective: To investigate associations between social integration and dementia risk by conducting a systematic review and meta-analysis of the literature.

Method: A search of PubMed, EMBASE, PsycINFO, CINAHL, LILACS, Biomed Central, Scopus and Web of Science databases was performed to identify articles published between 01 January 2012 and 26 May 2017, supplemented by extraction of all longitudinal studies to July 2012 from previous reviews. Cohort and case-control studies examining the association between social engagement or loneliness and dementia risk were included. We used aggregate-level data in a random effects model to produce pooled risk estimates for the association with dementia risk for loneliness, as well as good and poor social engagement. Study quality was assessed with the Newcastle-Ottawa Scale. Registered with PROSPERO (CRD42017067074).

Result: We identified 35 studies comprising 2,370,452 participants for inclusion. Poor social engagement, operationalized as living alone, poor social network, few social contacts and poor social support were all associated with increased dementia risk. Overall, good social engagement was protective against dementia, but was marred by significant publication bias ($p < .001$). In studies with a long follow-up time of ten or more years, and thus less prone to reverse causation, good social engagement was modestly protective against dementia. Loneliness was associated with a non-significant increased risk of dementia.

Conclusion: Elucidation of causative neurobiological mechanisms and investigation of potential reverse causation bias is necessary to draw firm conclusions. Our findings encourage interventions targeting social isolation and disengagement for dementia prevention.



PARALLEL SESSION ABSTRACTS

Youth and dementia

Date: Saturday, 28 July 2018

18-001

DEMENTIA SUPPORTER TRAINING SESSION FOR YOUTH: CREATING DEMENTIA FRIENDLY COMMUNITY TODAY AND TOMORROW

Ms. Noriyo Washizu*, Alzheimer's Association Japan, Kyoto, Japan

Abstract:

Japan is the world's fastest ageing country —more than 27% of our population is over the age of 65 in 2016 and by 2025 we estimate that 1 in 5 people over 65 will have dementia. As our population continues to age there will be a significant gap between young and old. And what if the younger generation doesn't know what dementia is? How will they react? How will they support their family members with dementia? What will happen to their relationships?

Dementia Supporter Caravan has been conducting a national campaign to make everyone a Dementia Supporter, including children and young people. The campaign is very simple. Everyone who participates in a 90 minutes course can be a Dementia Supporter. The required course is set by the Ministry of Health, Labor and Welfare but it can be arranged to accommodate the participants. 1.8 million out of 10 million Dementia Supporters in Japan are in their teens and 20s. Many elementary schools and junior high schools have incorporated dementia supporter training courses in the formal school curriculum and the number is increasing year by year. Also there are many universities and high schools which offer the course as seminars or volunteer activities.

Raising awareness and nurturing the mindset of a Dementia Friendly Community concept for youth are very important from three points of view. Firstly, youth and children are fast learners and have the potential to understand dementia without any stigma or prejudice. Education during the period of character formation is effective and it will have an effect on their entire lives. Secondly, they can spread the ideas to their family members. Actually, we have many cases in which they motivated their parents to learn about dementia and take training courses. Thirdly, their generation will take a leading role in supporting a society with twice or triple the number of people with dementia as the number is estimated to reach 131.5 million in the world and 10.1 million in Japan by 2050. They need to adopt the mindset of living together with people with dementia based on a correct understanding and a positive attitude to create Dementia Friendly Communities.

This report will include coverage of the actual practices, related interviews and analysis of the outcome. To look into dementia supporters training sessions for youth and children in the present situation and assess its outcome is a significant step in creating Dementia Friendly Community Today and Tomorrow.





PARALLEL SESSION ABSTRACTS

Youth and dementia

Date: Saturday, 28 July 2018

18-002

ADI GLOBAL YOUTH ABSTRACT: DEMENTIA IN MY FAMILY – SUPPORTING YOUNG PEOPLE AFFECTED BY DEMENTIA

Carol Vickers¹ and **Nigel McPaul**^{1,2}, (1)Dementia Australia, Barton, Australia, (2)Client Services, Dementia Australia, Canberra, ACT, Australia

Abstract:

Dementia Australia would like to work with Alzheimer's Society and Iran Alzheimer Association and present the below as part of a parallel session. If this is not possible we would look to combine abstracts into one global youth presentation.

Recognising that children are also impacted when someone they love has dementia is an important step in providing them with the support they need. The *Dementia in My Family* project was developed in response to a significant gap in appropriate, meaningful child-focused resources for children of all ages impacted by a family member's dementia diagnosis.

The website is divided into age group sections and explains dementia through easy to understand language, games and videos. It also includes a section for adults with tips on how to support and communicate with children and teens about dementia.

The project commenced in 2013, with a small grant that funded Dementia Australia to conduct an audit of available child-focused resources. This was supplemented with anecdotal evidence provided by family clinicians and support services in Victoria regarding what these children considered would be of most help to them. A consistent response was the need for a child-focused website.

In developing a child-focused website, Dementia Australia conducted an online survey of children, young people and adult members of Dementia Australia's consumer advisory committee. The purpose of the survey was to identify what survey participants wanted to see in such a website and how a site focusing on children and young people should look and feel. The subsequent development of the *Dementia in My Family* website undertaken with extensive consultation from health professionals, consumer and young people who helped with trialling and testing of the site. Furthermore, young people contributed stories to the "share your story" web pages and were also directly involved in the video productions for the two teenaged sections, 'Impact on you'.

Dementia Australia has continued its work with young people and is currently working with the University of Wollongong as part of the university's *Festival of STEM* which showcases studies and careers in Science, Technology, Engineering and Mathematics for an audience of high school students. As part of the *design based engineering* classes scheduled across the festival, student (aged 13 to 14 years) are tasked with generating ideas and solutions for developing *Dementia Friendly Communities*. By participating in these activities the students learn how *Dementia Friendly Communities* are designed to support and actively engage people living with dementia in their communities, while improving general awareness of dementia within their communities.



PARALLEL SESSION ABSTRACTS

Youth and dementia

Date: Saturday, 28 July 2018

18-004

DEMENTIA AWARENESS AND EDUCATION PROJECT FOR ELEMENTARY 5TH GRADERS AND FAMILIES IN IRAN

Faraneh Farin^{*1}; Manizheh Ahmadi²; Masomeh Salehi³ and Mehrdad Khansari³, (1)International, Iran Alzheimer's Association, Tehran, Iran (Islamic Republic of), (2)Education, Iran Alzheimer's Association, Tehran, Iran (Islamic Republic of), (3)Iran Alzheimer Association, Tehran, Iran (Islamic Republic of)

Abstract:

Iran Alzheimer Association would like to work with Alzheimer's Society and Dementia Australia and present the below as part of a parallel session. If this is not possible we would look to combine abstracts into one global youth presentation.

Dementia affects individuals, families, healthcare systems and has a profound impact on socio-economics of countries. Raising awareness and educating the public can have a significant effect on controlling risk factors of the disorder, receiving early diagnosis and start a treatment all of which would lead to reducing cost and delivering best practice care to people with dementia.

In 2013 we developed the "Dementia Awareness and Education Project for Elementary 5th Graders and Families". The aim of this project was to enhance awareness of dementia among elementary school children, informing them about the risk factors encouraging them to change their attitude towards people with dementia, reducing stigma and support the family care-givers. The awareness raising was also extended to their respective families. It is hoped that awareness which is raised at an early age will be retained in the brain for a long period of time resulting in reduction of prevalence and socio-economic cost of dementia in future.

The information provided in the packages enabled the children to be more aware of what goes on in the family care-giver's life and helped to change their attitude towards a person with dementia. Increased understanding of dementia can help them to avoid emotional crisis which itself can reduce psycho-social costs of dementia. They will also find it easier to spend more quality time with the person and be by the side of the family with the ongoing dementia journey.

IAA was able to execute the project for 4500 families with a limited number of manpower and reduced cost. It is still one of the best dementia awareness raising projects which has been executed in Iran and is applicable to any age group.

Feedback after the project, from both young people and adults, showed that 91.57% thought the project gave them a better understanding of dementia and 55% of families with a case of dementia stated that they had seen behavioral changes in their child.

Since then, in 2017, we tried a different approach by means of entering a school's environment and raise awareness directly for 5th and 6th grades. Parents were invited to participate in the following session. Both sessions were very well attended with great interest.

This experience was totally different from our first. In the recent one, we were in direct contact with both audiences. Children who had experienced dementia in their families had much concern about their parents and themselves. They expressed their worries through discussing them with the facilitator. Parents had many questions about how to deal with their children who were suffering from depression and anxiety. Our former training missed the valuable opportunity of direct contact.

We have also translated Alzheimer's Society's 'Memories with Grandma' animation into Farsi, so there is another resource available to raise awareness and understanding in young people and children.

We hope through educating young people, we will address the stigma that currently exists, and bring about



PARALLEL SESSION ABSTRACTS

early diagnosis. More training on care and dementia friendly communities are planned for the future to serve better people with dementia and their care partners across the country.

'It is good to understand why grandma is acting strangely, now that I know the symptoms'





PARALLEL SESSION ABSTRACTS

Youth and dementia

Date: Saturday, 28 July 2018

18-005

YOUTH EMPOWERMENT PROGRAMS FOR BUILDING DEMENTIA FRIENDLY KOREA

Soyeon Kim¹; Seonjeong Byun²; Ki Woong Kim² and **YunHye Jo**^{*3}, (1) National Institute of Dementia, Seongnam, Korea, Republic of (South), (2) Department of Neuropsychiatry, Seoul National University Bundang Hospital, Seongnam, Korea, Republic of (South), (3) Strategic Business Dept., National Institute of Dementia, Seongnam, Korea, Republic of (South)

Abstract:

The number of people with dementia (PWD) was over 0.7 million in 2017 but will reach 2 million in 2039 in Korea, which is the most rapid increase in the world. However the birth rate is lowest in the world. Therefore the empowerment of younger generation is crucial for them to expect their burdens of dementia, to understand their roles in preparing dementia friendly society, and to develop visions to overcome dementia.

The Korean National Institute of Dementia (KNID) is running three programs for empowering Korean youth to be prepared for dementia epidemic. First, we started the **Dementia Friendly School (DFS) Designation Program** in 2015. To be designated as a DFS, all school members including both students and teachers have to complete the education program for Dementia Partner and to become dementia partners. Until the end of 2017, 147 schools across the country joined this program. Second, we have held the **National Dementia Awareness Student Contest** every year since 2013. Not only will this program help the youth develop their potential as dementia friendly leaders, it will energize and inspire them to discover their own power to be influential community leaders. Middle or high school students can apply to the contest as a team. In the contest, they are asked to complete the several missions given by the KNID. Based on the creativity, excellence and influence, a minister prize from the Ministry of Health and Welfare and director prizes from the KNID are awarded. Since 2013, 1,032 students (237 teams) joined this contest, and developed excellent programs for enhancing dementia awareness in Korea. Third, we launched the **Healing Atti School** in 2013. Atti means friends in Korean. This program provides high school students with the education on dementia and the volunteer program at the KNID during their summer and winter vacations. Since 2013, 284 high students completed this program.

We believe these youth empowerment programs will raise future leaders who will make the Korean Society more dementia friendly.

Key words: dementia, youth, school, awareness, leader

We would like to present the below as part of a parallel session on global youth engagement. If this isn't possible the abstract may be considered as a poster presentation.



PARALLEL SESSION ABSTRACTS

Youth and dementia

Date: Saturday, 28 July 2018

18-006

“YOUNG PEOPLE, THEY JUST GET IT!” WORKING ACROSS GENERATIONS TO ACT ON DEMENTIA

Sarah More¹; **Sally Copley**² and Philippa Tree¹, (1)Alzheimer's Society, London, United Kingdom, (2)Policy, Campaigns and Partnership, Alzheimers Society, London, United Kingdom

Abstract:

Almost everyone knows someone affected by dementia. Yet, those with the condition, their family, friends and carers still face widespread stigma and social exclusion. Young people are no exception. So how do you explain dementia to a young person? And why is it important to do so?

Explaining dementia to young people can feel overwhelming and many may find changes in loved ones difficult to understand. However there are lots of resources to help parents and teachers explain these changes and begin a wider conversation about dementia.

What resources are available?

Alzheimer's Society (AS) has several resources to promote young people's understanding and acceptance of the condition, from school teaching resources, Dementia Friends activities to factsheets.

Partnerships with youth organisations such as The Scouts Association help to spread this awareness further and encourage action in every community.

The Scout Association's '[A Million Hands](#)' initiative encourages Scouts to take social action on dementia and work towards their Community Impact badge. Many have become a [Dementia Friend](#) and are now working with their local communities to create dementia-friendly spaces, including delivering activities in local care homes and creating dementia-friendly signage.

“Young people are so open and willing to learn that it almost doesn't occur to them to have the prejudices and negative perceptions that older people tend to have picked up.” - Bruce Moore, Dementia Friends Champion

Memories with Grandma

Our latest resource, '[Memories with Grandma](#)' is an animation for 7-11 year olds – www.alzheimers.org.uk/memorieswithgrandma.

We developed, reviewed and edited the script following feedback from three Service User Review Panels which consisted of 19 people with dementia. We consulted with members of the Global Dementia Friends network to ensure the animation could be used in different cultures and countries. We also held youth focus groups with over 30 children of our target age. Not only did our consultees tell us their preferences but they also made valuable contributions to the script and style of the animation.

Dianne Campbell, AS ambassador living with dementia, voiced Grandma.

‘It's great to have been involved with a project that is actively raising awareness of dementia with younger generations. It is so important that they learn about dementia because they are our future doctors, politicians, teachers... By educating people at a young age we are transforming the landscape for those affected by dementia today and in years to come’.

There are two versions of the animation, one which can be used by teachers in the UK, and alongside a lesson plan can be used to create Dementia Friends. There is also a version which has been adapted so other Alzheimer associations can use it. It is subtitled in Spanish, French, Mandarin and Arabic, and has been adapted by Alzheimer's Indonesia and Iran Alzheimer Association.



PARALLEL SESSION ABSTRACTS

Since its launch in September 2017 the animation has been viewed on YouTube over 4,000 times by people from over 63 countries!

"Dementia is a global health epidemic. However, if we continue to educate and stand united across all generations and cultures, we can address the challenge of dementia" - Dianne Campbell

This session will be co-presented with Dianne (person with dementia). We will present a range of youth resources that can be used & adapted worldwide. We'll discuss our development process, the animation, and share the impact our youth outreach is having on people living with dementia.



PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-001

ALZHEIMER'S: A LOVE STORY

Mr. Michael A. Horvich, ALZHEIMER'S: A Love Story, Evanston,, IL

Abstract:

After a 30+ year teaching career the presenter, Michael, has been retired for 20+ years but has been more than active as an educator, speaker, story teller, writer, poet, photographer, blogger, artist, jeweler, lecturer, actor, supernumerary, museum curator, flea circus ring master, philanthropist, and Dementia/ Alzheimer's caregiver partner for his life partner Gregory (RIP 2015.)

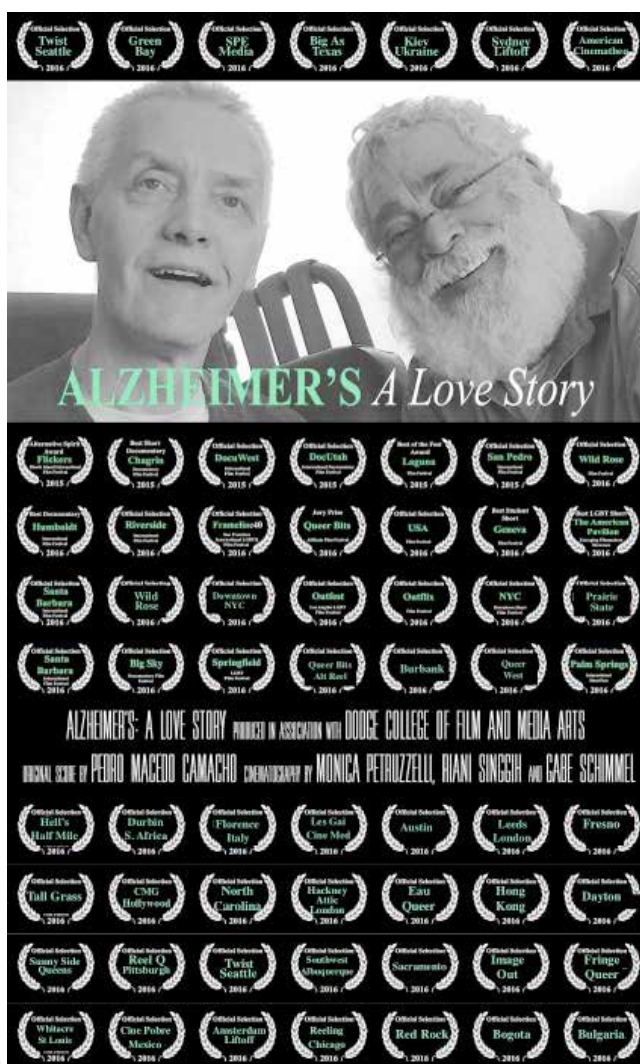
Most recently, Michael has been speaking about Alzheimer's disease to groups like the NorthShore University Health Care System Division of Palliative Care and Hospice, the United Methodist Church of LaGrange Illinois, University of Chicago Middle School Students, the Lieberman Center for Health and Rehabilitation, the Sherman Plaza Book and Social Club, the Dementia Alliance International out of Australia, Pritzker School of Medicine, Northwestern University Kellogg Graduate School of Business, Great Lakes Alzheimer's Association, and the Battle Creek Congregational Church. He has booked several "one man shows" in a theater setting to take place during 2018; two in the Chicago area and on is Athens, Greece.

His life partner, Gregory was diagnosed with Dementia/Alzheimer's 15 years ago during the 29th year of their 41 year relationship. A 15-minute documentary, "ALZHEIMER'S: A Love Story," was made which follows them for a week, approximately 6 months before Gregory died. The documentary so far has been accepted by more than 90 film festivals in the U.S. and around the world and has won over 35 awards including two at the American Pavilion at the Cannes Film Festival.

As you hear Michael's presentation, the fact that it deals with a same-sex couple and Alzheimer's Disease begins to disappear. What emerges is a love story about any two people who love each other and what they face during a catastrophic, long term illness.

Michael will tell his ALZHEIMER'S love story in a way that is raw and honest, balanced between joy and sorrow, but none the less is uplifting and positive. The story he tells provides hope in what could be a hopeless situation! Gregory and Michael lived well with the disease, made the most of their time, and recognized the many gifts (as well as sorrow) that Dementia/ Alzheimer's can bring. Gregory, as Michael says, was not a victim of Alzheimer's ... he was a hero!

A reference sheet and link to the documentary will be provided.





PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-002

EMPOWERMENT IN ACTION: LIVING WITH DEMENTIA AND LEADING INCLUSIVE PARTNERSHIPS

Stephani L Shivers*, Community Services, LiveWell Alliance, Inc., 1261 South Main Street, CT; **Robert Savage***, Representing self, Plantsville, CT; James Taylor, Representing self, Sherman, CT and Daniel Belonick, LiveWell Alliance, Plantsville, CT

Abstract:

People living with dementia (PLWD) possess foundational human rights of respect, equality and inclusion. Embracing these rights and the philosophy of "Nothing about us, without us" heralded by Dementia Alliance International, this session showcases initiatives lead by and inclusive of PLWD and highlights ways a dementia service organization models inclusivity and empowerment in program/service development and implementation.

Session participants are mutually grounded in the beliefs that:

- Stigma, discrimination and myths about dementia are best combatted when people living with dementia are empowered to publically share their lived experiences
- People living with dementia are to be respected, included and recognized as valued contributors to society
- People living with dementia have the capacity to apply their direct experiences to the development and implementation of programs, services and resources designed to improve their lives
- Organizations and service providers must engage in inclusive partnerships which empower people living with dementia, their families and carers

The session is led by at least two individuals living with dementia and one spouse who are modeling ways to lead efforts to turn their experiences into actions driving change in stigma, public awareness, peer support, advocacy, research, and capacity to live well with dementia. The session also includes leaders from LiveWell (formerly Alzheimer's Resource Center) a not for profit dementia services organization in Connecticut who seeks to fundamentally shift the framework for how PLWD and their family members are being served, engaged and participate in issues of importance for them.

This session seeks to answer the questions: What does empowerment look like? Why is it necessary for PLWD? How are PLWD leveraging their experiences to shape society, services and resources? How might dementia service providers/professionals/advocates create opportunities for PLWD to lead and direct the field which seeks to serve them? Case examples on ways to include and empower PLWD in public awareness events, service design and implementation, dementia friendly initiatives, research initiatives, organizational governance, professional development and education will be highlighted.

Session topics will cover:

1. Key values and human rights which underpin empowerment and inclusion
 - o Drawing upon resources from Alzheimer's Disease International, Dementia Alliance International, Convention on the Rights of Persons with Disabilities, AlzScot Charter of Rights
2. Challenging stigma and changing public perceptions through: art, storytelling, public awareness/education events, dementia friendly initiatives
3. Peer driven support and education initiatives by people living with dementia and/or spouses
4. Driving research development and implementation
5. Supporting empowerment through inclusive partnerships



PARALLEL SESSION ABSTRACTS

6. Ways to get involved

Learning Objectives: Learn foundational values and principles necessary for the empowerment of PLWD

- Learn how PLWD are leading and directing initiatives to change society, culture, programs and services
- Understand innovative and replicable ways dementia service organizations can partner with and support the empowerment PLWD in their organizations
- Discover how to lead or join local/state/national initiatives promoting inclusive opportunities





PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-002

EMPOWERMENT IN ACTION: LIVING WITH DEMENTIA AND LEADING INCLUSIVE PARTNERSHIPS

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- People living with dementia have the capacity to apply their direct experiences to the development and implementation of programs, services and resources designed to improve their lives
- Organizations and service providers must engage in inclusive partnerships which empower people living with dementia, their families and carers

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This session seeks to answer the questions: What does empowerment look like? Why is it necessary for PLWD? How are PLWD leveraging their experiences to shape society, services and resources? How might dementia service providers/professionals/advocates create opportunities for PLWD to lead and direct the field which seeks to serve them? Case examples on ways to include and empower PLWD in public awareness events, service design and implementation, dementia friendly initiatives, research initiatives, organizational governance, professional development and education will be highlighted.

Session topics will cover:

1. Key values and human rights which underpin empowerment and inclusion
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2. Challenging stigma and changing public perceptions through: art, storytelling, public awareness/ education events, dementia friendly initiatives
3. Peer driven support and education initiatives by people living with dementia and/or spouses
4. Driving research development and implementation



PARALLEL SESSION ABSTRACTS

5. Supporting empowerment through inclusive partnerships

6. Ways to get involved

Learning Objectives: Learn foundational values and principles necessary for the empowerment of PLWD

- Learn how PLWD are leading and directing initiatives to change society, culture, programs and services
- Understand innovative and replicable ways dementia service organizations can partner with and support the empowerment PLWD in their organizations
- Discover how to lead or join local/state/national initiatives promoting inclusive opportunities





PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-003

THE CARE HOME BAND PROJECT: FINDINGS FROM A NOVEL MUSIC INITIATIVE IN CARE HOMES WITH RESIDENTS, STAFF AND THE COMMUNITY

Laura Reynolds^{*}; Anthea Innes and Jane Robertson, Faculty of Social Sciences, University of Stirling, Stirling, United Kingdom

Abstract:

This paper will discuss the concept of a care home band. The care home band project seeks to create and evaluate a music initiative ('care home band') bringing together residents, care home staff and the community to rehearse and perform together in a creative, fun and sociable atmosphere. Based on an established community model, it encourages care homes to use active music making and performance to engage residents and foster connections with local communities.

Music has the potential to enhance feelings of well-being, increase positive social interactions, and provide an increased sense of empowerment and control for people with dementia. Many initiatives forgo the norms of music making, such as rehearsing and performance cycles. Indeed, most research is done 'for' rather than 'with' people with dementia despite evidence to suggest people with dementia are most engaged when actively participating in activities. Performances provide constructive meaning to music making and allow for opportunities to connect with local communities. They may also contribute to feelings of pride and empowerment for performers and challenge current negative stereotypes of dementia. In addition, music initiatives often conclude after a fixed intervention period, potentially leading to a sense of loss by participants. To address this, the project encourages staff to create a music group with residents and the community that becomes part of the life of the care home.

Two UK care homes participated in this exploratory project (one in England; one in Scotland) with one band created per care home. Care home staff implemented the music initiative following a workshop with professional musicians and the project team in each care home. The workshops encouraged participant ownership of band by enabling staff to cultivate their ideas about the creation of the bands, such as resources, repertoire and resident needs. Participating staff led a ten-week rehearsal and performance cycle with residents, other staff members and the community, culminating in a public performance to showcase each care home band's achievements. Semi-structured interviews were conducted with participating staff and residents, in addition to ethnographic field notes and structured observations (Dementia Care Mapping). Staff also completed a log of activities contributing to the development of the music initiative within the care home. The public were invited to complete a short questionnaire during the public performances.

Initial findings will be discussed, including resident and staff experiences of participating in the music groups. Obstacles and facilitators to the creation and development of the bands will be debated. In addition, the care home bands' sustainability beyond the life of the project will also be explored alongside public perceptions of the care home and dementia. These findings will contribute to a practice guide for those wishing to develop their own music initiatives in care settings for residents, care staff and the community. This paper will demonstrate the potential of music, via the medium of a care home band, to change the 'rhythm of care' in care home settings.



PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-004

MY HUMAN RIGHT TO ENJOY LIFE, EVEN WITH DEMENTIA: THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AS A GUIDE TO A LIFE WORTH LIVING

Dr. Mary L. Radnofsky Ph.D^{*}, Once Human, Forever Human, Alexandria, VA

Abstract:

Life, dignity, freedom, justice, health, decision-making, education and other basic human rights of people with dementia are protected under the United Nations 2006 Convention on the Rights of Persons With Disabilities (CRPD), ratified by 175 countries.

As the first person with dementia to speak at the UN on the rights of people with dementia, I became familiar with the Convention and now use my experience to identify services, resources, and practices to help create environments conducive to living well with the disability of dementia, as is our due (CRPD, Article 10). In this session, we discuss how to create those environments.

This right to enjoy life involves access to “civil, political, economic, social, and cultural spheres with equal opportunities” (CRPD, Preamble). No cognitive standard is set, so people with degenerative brain diseases deserve the same chance to enjoy living as others. To do this, we need support, access, legislation, trained professionals, assistive technology, other resources and services (CRPD, Article 4).

However, based on the biomedical model of care for people with dementia, the traditional focus has been on ensuring our survival and safety, often to the detriment of a life worth living. While safety is important, of course, it is not the ultimate goal of living. Instead, as humans, we seek fulfillment and happiness in interpersonal relationships, love, giving, sharing, building things that matter, connecting with nature, creativity, spirituality, moving and challenging ourselves to learn or do more, and finding purpose both individually and collectively – with or without dementia.

Governments, residential facilities, even families must ensure and respect these rights. And given that the changing needs of people with degenerative conditions are difficult to ascertain and address, carers must make use of all possible alternative means, modes and formats of communication (CRPD, Article 21) to learn our preferences.

Unfortunately, even well-meaning institutions and care partners often take control over our lives. Such substitute decision-making is antithetical to the Convention, which holds we be actively involved in decisions that affect us (CRPD, Preamble, Article 4). Efforts must be made to allow even people in later stages of dementia to clearly express their will (e.g. physically, non-verbally).

Certain mechanisms of human rights must also be in place to ensure that once we make a decision, it is not overridden. For end-of-life care, we know that medical directives already exist. But decisions on how we want to live now and keep living – not only die – must be made clear, too. These include participating in recreation, culture, and sports, for example (CRPD, Articles 10, 30), where to live, with whom, and without fear of segregation, isolation, or having our privacy invaded (CRPD, Articles 19, 22).

We're still human, and we have rights. Once human, forever human.



PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-005

A NEW CHALLENGE OF JAPAN DEMENTIA WORKING GROUP – TO CREATE A SOCIETY WHERE WE CAN LIVE WITH DEMENTIA IN OUR OWN COMMUNITY BY RIGHTS

Kumiko Magome*; Kazuko Fujita and Kumiko Nagata, Japan Dementia Working Group, Rm.203, 2-9-8 Minami Ikebukuro, Toshima, Tokyo, Japan

Abstract:

Japan Dementia Working Group (JDWG) was founded in 2014, by the people living with dementia at its core of the organization, with support of different professionals and willing friends. It aims at working for creating a society where the people with dementia can live in our own community “by rights” with dignity and hope, whichever parts of Japan we may live. In 2017, JDWG became socially incorporated to strengthen its structure and further extend its activities throughout Japan, while globally developing alliance with other organizations of people with dementia outside of the country. At ADI Kyoto 2017, JDWG gave a presentation “*Relay of Hope*,” representing the collective voices of people with dementia and their carers and supporters. The video of the title was shown and well accepted.

The presentation for ADI Chicago 2018 will be an overview of the JDWG activities, achievements, and challenges since 2014. One of the major achievements of JDWG is that we helped the Japanese government to share the perspective of “Nothing About Us Without Us.” Our voices were heard and implemented in the making of New Orange Plan (Jan., 2015), the national dementia policy, in which it stated to “prioritize the perspective of those with dementia,” and to “include people with dementia in the planning, the making, and the evaluation of national policy.” Now we see different municipalities trying to change their policies and transform their practices based on the perspective of those with dementia.

Yet, we also see that there are huge gaps among municipalities and the future of those with dementia might depend on where they live. In order to evolve from this stage, we are currently promoting to (1) hold a local meeting of people with dementia to share our experiences and make proposal to the local government and community, (2) initiate an action meeting to involve different parties to take an action together, and (3) promote our activities to create webs of people and activities. These efforts are also aiming at giving helping hands to remote communities with very limited resources.

We are beginning to witness that the people with dementia meet each other at an early stage, in their own local community, with carers and supporters. We talk about our hope, feel secure and relaxed, and enjoy engaging in our activities. Our presence give hopeful reality to people that “we can live better with dementia.” We also help reducing the vicious stigma of dementia. JDWG will continue to work so that every person with dementia can live better in community. We hope to create a “wave” at a national level, making more global friends to hold our torch of hope together.

This presentation was jointly developed by the JDWG board members with dementia and those without dementia, and it will be co-presented by JDWG member(s) and supporting partners including a translator. Short video messages may be added in case we do not have enough member presenters participating at the venue due to health, financial and other reasons.

PARALLEL SESSION ABSTRACTS

Engaging people living with dementia and care partners

Date: Saturday, 28 July 2018

19-006

THE FANTASTIC ADVENTURE – HAVING FUN WITH FARMING!

Hui-Ya Lin¹; Zhong-Han Lee¹; Chun-Chun Chen¹; Dr. Chien-Liang Liu² and Shiou-Sheng Chen², (1)Zhongzheng District Health Center, Taipei, Taiwan, (2)Taipei City Hospital Heping Fuyou Branch, Taipei, Taiwan

Abstract:

Objective: Despite being only 36,000 km² in area, Taiwan is rich in natural and cultural resources and thereby earns the name “Formosa”. Its unique agricultural environment has attracted many breeders and farmers. Agriculture used to have quite successful development and made a great contribution to economic growth of Taiwan. Therefore, agriculture had been the basis for the livelihood of the elderly for a long time. However, with changes in the economic structure, the juniors are not willing to engage in farming.

By the end of 1971, agriculture had “successfully retired”. The glorious achievement of agriculture becomes the long term memory of the people living with dementia and care partners. Nowadays, the instruments and photos of agriculture are displayed in the museum. Therefore, we wanted to utilize these cultural heritages to remind the people living with dementia and care partners of the glorious achievement and enhanced the extent of social engagement of them.

Method: We utilized the instruments and photos of agriculture to design a 12-week course related to farming in the museums. We also added elements of exercise and brain storming to the courses, further enhancing physical fitness and delaying the progress of dementia. By sharing experience of the past agricultural times and ways of making traditional cuisines with crops of farming, we stimulated motivation of social engagement of people living with dementia and care partners. Moreover, the administer of the museum provided us a land in the museum to grow and harvest produce. By showing their best skills of farming, people living with dementia and care partners can enhance self-confidence and are more willing to engage in the community.

With higher extent of social engagement, people living with dementia and care partners can be more positive and reduce the level of depression. Therefore, we utilized the Geriatric Depression Scale-15 (GDS-15) to evaluate the efficacy of the intervention.

Result: 20 participants with 5 males and 15 females engaged in the courses. All the participants were interviewed and did the GDS-15. The average reduction of depression index derived from the GDS-15 is 2.1 ($P < 0.05$). According to the care partners, people living with dementia became calm and less agitated with higher level of social engagement.

Conclusion: By collaborating with the museums, we utilized the culture background of people living with dementia and care partners to enhance social engagement. The result showed that our way had a positive effect on social engagement. Due to the homogeneous culture background of Taiwan, our successful way of engaging people living with dementia and care partners can implement in other areas of Taiwan.





Acute and palliative care

Date: Friday, 27 July 2018

2-001

THE CARE OF PEOPLE LIVING WITH DEMENTIA IN ACUTE HOSPITAL WARDS: RESULTS FROM AN ETHNOGRAPHIC STUDY

Katie Featherstone Dr*, School of Healthcare Sciences, Cardiff University, Cardiff, United Kingdom and Andy Northcott Dr, School of Allied Health Sciences, De Montfort University, Leicester, United Kingdom

Abstract:

Objective: People living with dementia admitted with an unrelated condition are one of the largest populations cared for within the acute hospital setting, currently using from one quarter (Alzheimer's Society, 2009) to up to 40 and 50% (Alzheimer's Society, 2016) of UK acute hospital beds at any one time. Yet, the care of their dementia diagnosis is often not recognized by clinical staff as a priority (Tolson et al., 1999) or they are deemed an 'inappropriate' admission (Rockwood & Hubbard, 2004:429). Clinical staff routinely believe that this patient group do not belong within the acute setting (Tadd et al, 2011) and should be transferred to other services (Moyle et al, 2008).

Hospitals are failing to respond to the needs of an ageing population in the context of increasing hospital admissions for this population (RCP, 2012). This means there is an urgent need for ward staff to develop specific care practices that brings together the care of a person's dementia diagnosis with their acute admitting condition (Hart et al, 2002).

Method: In response, this paper draws on empirical findings of an in-depth ethnographic study in 10 wards within 5 hospitals across England and Wales, purposefully selected to represent a range of hospitals types, geographies and socio-economic demographics. Across these sites, 155 days of observational fieldwork were carried out in areas of acute hospitals known to admit large numbers of people living with dementia for an unrelated acute condition: Trauma & Orthopaedic wards and Medical Assessment Units. Approximately 600,000 words of observational fieldnotes were collected, transcribed, cleaned and anonymised by the authors, 436 ethnographic interviews conducted in the course of the everyday life of the ward, taken from 155 participants including ward staff, carers and patients themselves. Detailed case studies were also conducted with 10 people living with dementia, observing their care at the bedside and speaking to the person, their family and carers throughout their admission.

Result: We identified extremely high levels of resistance to care amongst people living with dementia within acute hospital wards. It was a common feature of ward life; every person living with dementia we observed admitted within the acute hospital ward resisted care during our period of observation. Importantly, resistance, in whatever form it manifested, was always interpreted by staff as a feature of the person's dementia diagnosis that signified their lack of capacity, and as such was interpreted as a behaviour to be overcome or managed. However, our observations identified that resistance was typically a response by people living with dementia to the organization of their care within the wards (fixed routines and timetabled demands) and the ways in which ward staff delivered care at the bedside. In response, ward staff used multiple interactional approaches that focussed on reminding the person of the 'rules of the ward' and on containing and restraining the person living with dementia at the bedside or in the bed.

Conclusion: We show the emotional and somatic impacts of these approaches for people living with dementia and the ways in which a diagnosis of dementia becomes framed as risk within the ward that must be controlled and contained at the bedside. We outline our current ward based interventions and training focused on the organization of the ward and staff interaction at the bedside to support nurses and healthcare assistants to improve care for people living with dementia.



PARALLEL SESSION ABSTRACTS

Acute and palliative care

Date: Friday, 27 July 2018

2-002

THE IMPORTANCE OF PALLIATIVE CARE FOR PEOPLE LIVING WITH DEMENTIA

Stephen R Connor*, Worldwide Hospice Palliative Care Alliance, Fairfax Station, VA

Abstract:

Caring for people with dementia at the end of life poses significant challenges. Hospice and palliative care services are increasingly being used to support caregivers and to address suffering. The proportion of people with dementia receiving palliative care is growing and is the third highest hospice diagnosis in the United States at 16.5% of admissions. In this session participants will explore how palliative care benefits people living with dementia including common symptom management problems, patient and family education, respite care, psycho-social and spiritual support, practical assistance, legal and professional assistance, and preservation of dignity. Also included are guidelines on when to initiate palliative care and how to develop an interdisciplinary plan of care. Until there are cures for dementia palliative care will continue to be an essential part of the continuum of care for people living with dementia.





PARALLEL SESSION ABSTRACTS

Acute and palliative care

Date: Friday, 27 July 2018

2-003

CARING TILL THE END: EXPERIENCES OF HOME CARE WORKERS OF PEOPLE WITH ALZHEIMER'S DISEASE UP TO THE END OF LIFE

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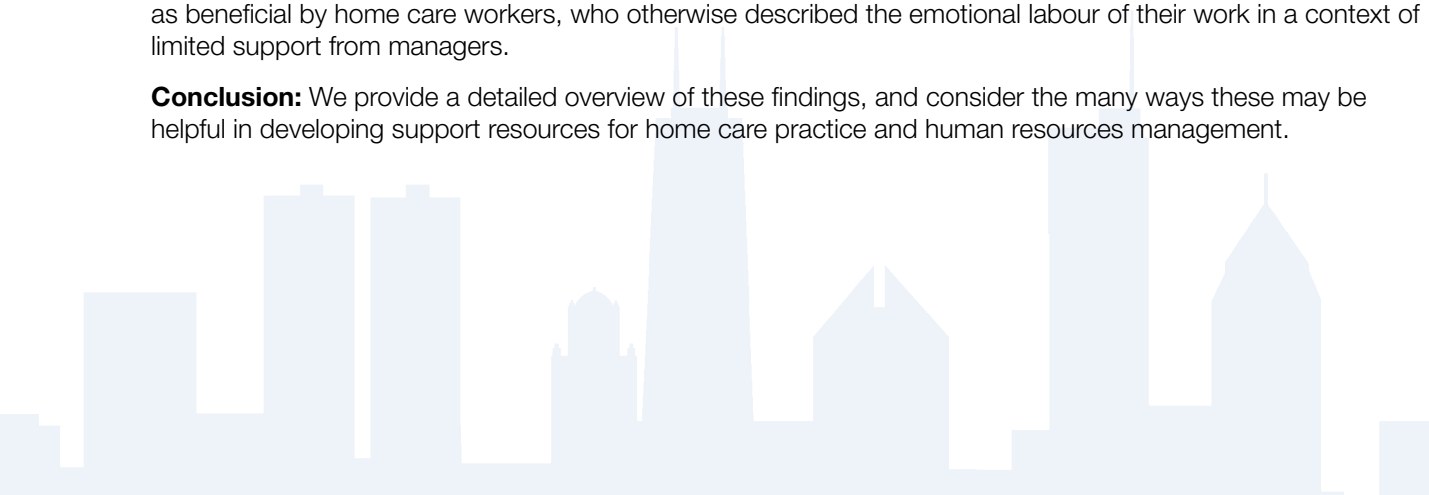
Abstract:

Objective: Many people with Alzheimer's disease who are living in their own homes receive care and support from home care agencies often until life's end. Yet, their experiences and beliefs about providing care at life's end have been largely ignored in research, including any changes in role and relationship. The impact of client's death upon home care workers is also rarely researched.

Method: We undertook qualitative face to face interviews with 28 home care workers and 12 managers of home care agencies in the U.K. in 2017 following a literature review and consultation with family carers and older people. The interviews covered details of everyday work, with specific focus on any changes as their client moved towards the end of life, and how the care workers negotiated such changes. We used overarching questions to separate transcripts into meaningful fragments and delineate into themes. Any cross-cutting themes were annotated.

Result: Home care workers described undertaking functional tasks of toileting, feeding and bathing within a caring relationship of compassion, dignity and patience. However, there were finer nuances to their role as their client neared end of life and client feedback and responses became increasingly limited. Many described working on the basis of using their personal intuition, honed by experience. Almost all home care workers described a 'good death' in terms of it being pain free, in a place of one's choosing and being surrounded by loved ones. Beliefs did not markedly differ about how these wishes could be met. However, the difficulty of maintaining role boundaries was described by many, and for some this extended to conflict between family carers and home care workers about their remit; and how these tensions were circumvented. As the health and decision making capacity of a client deteriorated, fulfilling one's professional duties while respecting clients' autonomy left some homecare workers feeling helpless and dissatisfied at times. The absence of client feedback made it difficult for workers to personally determine where the boundaries of 'good' care exist. Some homecare workers felt ill equipped at times to deal with the grief of family members and struggled to provide emotional support. Many described finding formal contexts, such as supervision, and procedures, such as employers' policies, beneficial as these provided frameworks within which to operate, and clarified the boundaries of their work. Being prepared for a client's death and having the option to attend the client's funeral were both described as beneficial by home care workers, who otherwise described the emotional labour of their work in a context of limited support from managers.

Conclusion: We provide a detailed overview of these findings, and consider the many ways these may be helpful in developing support resources for home care practice and human resources management.





PARALLEL SESSION ABSTRACTS

Acute and palliative care

Date: Friday, 27 July 2018

2-004

CAREGIVERS' BELIEFS TOWARDS UNDERTAKING ADVANCE DIRECTIVES

Ms. Ile Kermel Schiffman* and Perla Werner, Department of Community Mental Health, University of Haifa, Haifa, Israel

Abstract:

Objectives: Discussing advance care plans and completing Advance Care Directives are increasingly recommended; especially since knowing a person's preferences for care can reduce decision making burden and worries among family caregivers. However, little is known about the reasons associated with engaging in this process, especially among caregivers of persons with dementia. The aim of this study was to examine the main beliefs associated with family caregivers' willingness to complete advance directives for themselves.

Method: Semi-structured interviews were conducted with 20 family caregivers of people with dementia. The majority of the participants were female (75%) and spouses (65%). Mean age was 66. Participants had an average of 15 years of education and had been involved in caring for the person with dementia for an average of 8 years.

Results: Three main beliefs emerged from the interviews as the basis for the decision: respecting the person's autonomy at end of life, not prolonging life unnecessarily, and alleviating the decision making burden of family members. Participants also mentioned that in the process of undertaking advance directives they would refer mainly to family members and friends. Internal factors such as previous familiarity and experience with Alzheimer's disease or worsening health were described as enabling factors, while technical difficulties and lack of knowledge or awareness regarding advance directives were voiced as barriers.

Conclusions: The findings of the study indicate that family caregivers' beliefs are diverse and involve personal, familiar and technical factors. Understanding the factors that facilitate the process of undertaking advance directives is crucial in order to improve the quality of care at end of life.





PARALLEL SESSION ABSTRACTS

Acute and palliative care

Date: Friday, 27 July 2018

2-005

CARING FOR PATIENTS WITH COGNITIVE IMPAIRMENT IN THE ACUTE HOSPITAL: CHANGING THE WARD ENVIRONMENT TO IMPROVE CARE

Susan Kurrle*, Cognitive Decline Partnership Centre, Sydney, Australia

Abstract:

In Australian acute hospitals, more than 30% of patients aged 65 years and over present with cognitive impairment, or develop it during their admission. For these patients with cognitive impairment there is an increased risk of falls and fall related injury, worsening functional decline, increased length of hospital stay, increased chance of medical and surgical complications, increased chance of institutionalization, and increased mortality. Managing these patients in a ward environment that is patient-centred and older person friendly is likely to lead to reduction in development of cognitive impairment, and shorter duration of illness.

The Confused Hospitalised Older Persons Program (CHOPs) is a model of care to improve recognition, assessment and management of delirium and/or dementia in patients in the acute hospital. It was initially piloted in five hospitals, and following refinement was more recently implemented in a further six hospitals in urban, rural and remote areas. It is a model of care that includes staff education and training to improve screening, assessment and management of delirium and dementia, and also includes information on modification of the ward environment to improve the care of older patients. As part of the implementation of the CHOPs program in each hospital, an environmental audit was conducted by an experienced clinician. This audit assessed each participating ward against published Principles for Improving Health Care Environments for People with Dementia. This included reviewing the layout of the ward, access, lighting, signage, availability of low low beds, availability of single rooms, presence of large face clocks and calendars, colour contrast, availability of appropriate chairs with arms by each bed, and access to lounge and dining areas, and to outdoor areas.

This presentation describes the results of the environmental audit in the six hospitals, including the issues identified, and recommendations for how to address these problems (see attached Table). It uses case studies to illustrate how the improvements were made and the benefits observed for older patients as a result of these improvements.

Overview of environmental audit recommended changes

Principle	Title	Changes to ward environment
1.	Unobtrusively reduce risks - safety	↑ availability of falls alarm mats ↑ availability of high low beds ↓ ward clutter
2.	Provide a human scale	↑ availability of single rooms
3.	Allow people to see and be seen - visual access	↑ visibility from nurses' station (prioritisation of patients with cognitive impairment)
4.	Principle 4 Reduce unhelpful stimulation - stimulus reduction	Strategies to ↓ buzzers and other noise for patients with cognitive impairment
5.	Principle 5 Optimise helpful stimulation - highlighting useful stimuli	↑ orientation clocks ↑ suitable toilet signs ↑ suitable shower signs ↑ toilets with contrasting seats New "Hello my name is..." patient friendly staff name badges New poster of ward staff
6.	Support movement and engagement - provision for wandering, circulation and access to outside area	Doors to exits and storage areas unobtrusive Pathway to common areas clearly signed Outdoor areas • wayfinding • Delirium brochures and admission care packs in wards Accessible outside area. • All wards had patient care whiteboards mostly visible from the beds and CHOPs magnets were in use for confused patients • The CHOPs icon was on the electronic journey board
7.	Create a familiar space- familiarity	Space provided for personal items Families encouraged to stay ↑ use of "Getting to Know You" tools ↑ availability of suitable arm chairs
8.	Provide a variety of spaces to be alone or with others	Accessible outdoor area and improvements to this space Natural light maximised ↑ availability of lounge/visitor rooms
9.	Provide links to the community - community links	↑ access to diversional activities (eg luggage box, fiddle mats)
10.	Support the values and goals of care	↑ use of patient care whiteboards Delirium brochures and admission care packs in wards CHOPs icon on electronic journey boards Delirium information in multiple languages



PARALLEL SESSION ABSTRACTS

Acute and palliative care

Date: Friday, 27 July 2018

2-006

PEOPLE WITH DEMENTIA TREATED IN ACUTE AND GENERAL HOSPITALS: THE SIGNIFICANCE OF FAMILY MEMBERS AND FAMILIAR CAREGIVERS

M.Jasmin Greskötter* and Wilfried Schnepf, Nursing Science, Witten/Herdecke University, Witten, Germany

Abstract:

Objective: Despite the increase of age-related mental diseases and the knowledge of specific needs of persons with dementia, acute and general hospitals in Germany are not well prepared. Often, dementia is a secondary diagnosis that significantly influences the main treatment. Combining the structural conditions of a hospital, the competences of the medical and nursing staff and the special needs of people with dementia in a right manner seems to be difficult. The unknown and noisy area, change of daily routines, hectic rush, incomprehensible nursing actions and therapeutical treatments as well as the lack of familiar caregivers are making the situation even more challenging for persons with dementia. This frequently leads to a decline of cognitive skills, further loss of independence and challenging behavior. Due to a lack of alternatives, patients with dementia are often sedated, fixed or discharged early. In this context the presence and knowledge of relatives and familiar caregivers is very important, as they stand for trust, confidence and safety. In this manner they can stabilize the care situation and act as a mediator between the hospital staff and the person with dementia. Furthermore, relatives are considered to be experts in the care of people with dementia. They know their life story and personal straits, their preferences and aversions very well and have the possibility to find a way of communicative access to the person with dementia even in an advanced stage of the disease. Therefore, it would be very helpful to use this expert knowledge systematically for all people involved.

Method: There is a lack of studies focusing on the significance of relatives and familiar caregivers being or feeling responsible for a person with dementia in need for hospitalization in an acute care setting. For this reason, a qualitative research design is used. To get an inside view and the meaning of the topic, the methods of grounded theory are applied. Semi-structured interviews with open-ended questions have been performed with people with dementia, family members, nursing staff, practitioners and social workers.

Result: First results show that family members and familiar caregivers have a high impact on the care situation and well-being, not only for the person with dementia but also for the hospital staff.

Conclusion: The aim of this study is to constitute the opportunities but also the limitations of the systematical involvement of trusted caregivers and the integration of their knowledge into the care process to improve the quality of care and well-being of people with dementia treated in acute or general hospitals.



PARALLEL SESSION ABSTRACTS

Epidemiology

Date: Saturday, 28 July 2018

20-001

STRIDE: A SYSTEMATIC REVIEW OF METHODOLOGIES AND OUTCOMES USED IN PREVALENCE STUDIES IN LOWER AND MIDDLE-INCOME COUNTRIES

Nicolas Farina¹; Adelina Comas²; Emily Freeman²; Sumaiyah Docrat³; Emiliano Albanese⁴; Martin Knapp² and Sube Bannerjee¹, (1)Brighton and Sussex Medical School, Brighton, United Kingdom, (2)London School of Economics, London, United Kingdom, (3)University of Cape Town, Cape Town, South Africa, (4)University of Geneva, Geneva, Switzerland

Abstract:

Developing policies to deliver effective care to people with dementia requires data on the current situation. However, with the exception of the countries that participated in 10/66 study, for most Lower and Middle-Income Countries (LMICs) there is very little data on dementia prevalence, quality of life, access to health and care services or impact of (unpaid) family care. The STRiDE project sets out to address some of these gaps, in part this will be achieved by generating new evidence of the prevalence, costs, and impact of dementia in two of the seven STRiDE countries (i.e. Kenya, Jamaica, Mexico, Indonesia, Brazil, South Africa, India). Prior to this we need to review evidence of existing prevalence studies in the STRiDE countries and other LMICs. In particular, we need to better understand the tools and methodologies used to conduct such a study in a culturally-sensitive manner. This presentation will highlight instruments and methodologies previously used in prevalence studies in LMICs, as identified in a systematic review. These findings will be presented within the broader context of the STRiDE project as well as the implications for the final data collection stage.





PARALLEL SESSION ABSTRACTS

Epidemiology

Date: Saturday, 28 July 2018

20-002

DESCRIPTIVE EPIDEMIOLOGICAL STUDY OF MENTAL DISABILITY ATTRIBUTED TO DEMENTIA IN THE PEOPLE AGED 55 YEARS AND OVER IN CHINA

Yueqin Huang^{*}; Zhaorui Liu; Hongguang Chen; Tingting Zhang and Yuanyuan Hu, Institute of Mental Health, Peking University, Beijing, China

Abstract:

Objective: To describe the prevalence and characteristics of mental disability attributed to dementia in the people aged 55 years and over in China, so as to provide scientific evidences for the prevention and rehabilitation of mental disability.

Methods: It is a secondary data analysis using data from the Second National Sample Survey on Disability. Prevalence ratios (*PR*) were estimated from Poisson regression with robust variance for the independent effects of related factors on the prevalence of mental disability attributed to dementia.

Results: The mental disability attributed to early-onset dementia was 0.89%, and the mental disability attributed to dementia in the people aged 65 years and over was 4.65%. The severity of multiple disabilities was higher than that of single disability, and mental disability attributed to dementia in the people aged 65 years and over was more severe than that of early-onset dementia. Persons with older age (*PR*=1.47), high school education or above (*PR*=1.66) and unmarried (*PR*=6.09) had higher prevalence of mental disability attributed to early-onset dementia, while persons living in western area (*PR*=0.58) had lower prevalence. In the people aged 65 years and over, female (*PR*=1.20), persons with older age (*PR*=2.71), high school education or above (*PR*=1.28) and with non-agriculture household registration (*PR*=1.26) had higher prevalence of mental disability attributed to dementia, while persons living in central (*PR*=0.38) and western areas (*PR*=0.53) had lower prevalence.

Conclusion: Attention should be paid to disability prevention and rehabilitation in the people aged 65 years and over with mental disability attributed to dementia and those with multiple disability causality. Women, elder persons, people with higher education level, unstable marriage status, non-agriculture household registration, and living in eastern area should be the key population for the prevention and treatment of mental disability attributable to dementia.



PARALLEL SESSION ABSTRACTS

Epidemiology

Date: Saturday, 28 July 2018

20-003

TRANSLATION AND VALIDATION OF 10/66 DEMENTIA DIAGNOSTIC BATTERY IN URDU IN KARACHI, PAKISTAN

Qurat ul ain Khan*, Psychiatry, Aga Khan University Hospital, Karachi, Pakistan

Abstract:

Objective: To translate and validate 10/66 dementia diagnostic battery in Urdu, in Karachi, Pakistan to determine whether it is suitable for case ascertainment in epidemiological research especially for people with low education.

Method: The 10/66 dementia diagnostic battery was translated and back translated in Urdu, and pilot tested. Total number of participants was 257 and included people 60 years of age and older. About half of them were recruited from the community and the other half from outpatient clinics at the Aga Khan University hospital, through advertisements, and nursing homes. DSM IV-TR was used to diagnose dementia and CDR global score was used to determine severity of dementia. People with mild and moderate dementia were included. AKUADS was used to screen for depression and DSM IV –TR criteria was used to diagnose depression. People with ≤ 8 years of education were included in low education group. People with more than 8 years of education were included in high education group. The discriminatory ability of 10/66 battery and its sub components was tested against the standard clinician diagnosis of dementia to ascertain its usability in population based studies.

Result: Average age of participants was 70 years and 121 were females. 128 had dementia and 129 had no dementia. Among those with no dementia, 40 had depression, 40 had low education, and 49 had high education. These are preliminary results and ROC analysis of the data is under way.

Conclusion: The results of this study will determine if 10/66 DRG diagnostic assessment can be used for ascertainment of dementia cases in epidemiological studies among Urdu speaking older population with low or no education.





PARALLEL SESSION ABSTRACTS

Epidemiology

Date: Saturday, 28 July 2018

20-004

FROM DEMENTIA EPIDEMIOLOGY TO POPULATION NEUROSCIENCE

Emiliano Albanese*, University of Geneva, Geneva, Switzerland; Mary Ganguli, University of Pittsburgh, Pittsburgh; Sudha Seshadri, University of Texas Health Science Center, San Antonio, TX; David A Bennet, Rush University Medical Center, Chicago; Kostas Lyketsos, Johns Hopkins University, Baltimore, MD; Walter A Kukull, University of Washington, Seattle; Ingmar Skoog, Gothenburg University, Gothenburg, Sweden and Hugh Hendrie, Indiana University Center for Aging Research, Indianapolis

Abstract:

Objective: Over recent decades, epidemiology has significantly contributed to advance our understanding of dementia, and to influence policy in progressive directions. Our aim was to review the opportunities and challenges facing dementia epidemiology in the new millennium

Method: Under the explicit assumption that dementia epidemiology should blend techniques and models from contemporary neuroscience with those of epidemiology and biostatistics to better serve public health and scientific research, we conducted a non-structured, highly interactive and participative exercise amongst a diverse group of senior dementia epidemiologists (N=8) to collectively answer the following question: how can epidemiology contribute to our understanding of dementia over the coming decades?

Result: There was unanimous consensus that dementia epidemiology should be re-framed as “population neuroscience”, which combines the tools and knowledge of epidemiology and cognitive neuroscience. Final agreement was reached on the following propositions: 1) On the basis of emerging evidence and newer paradigms and methods, population neuroscience is indispensable to minimize the bias typical of traditional clinical research, identify the relatively homogeneous subgroups that comprise the general population, and investigate broader and denser phenotypes of dementia and cognitive impairment; 2) Long-term follow-up of sufficiently large study cohorts are (still) required for the identification of cohort effects and critical windows of exposure; 3) Molecular epidemiology and omics will allow us to unravel the key distinctions within and among subgroups and better understand individuals' risk profiles; 4) Interventional epidemiology should be concerned with the identification of the different subgroups that respond to different treatment/prevention strategies; 5) The proposed strategies of population neuroscience should inform precision medicine; 6) Better understanding of the interactions between disease biology, personal and environmental factors, and social determinants of health will allow us to measure and track disease in communities and improve population health.

Conclusion: We propose re-framing dementia epidemiology as “population neuroscience”, because by placing neuroscience within a real-world context dementia epidemiology can fulfill its potential to serve both precision medicine and population health

**Epidemiology****Date: Saturday, 28 July 2018****20-005****ALCOHOL DRINKING STATUS AND COGNITIVE FUNCTION AMONG COGNITIVELY INTACT ELDERLY JAPANESE MEN**

Dr. Ali Tanweer Siddiquee¹; Aya Kadota¹; Akira Fujiyoshi¹; Naoko Miyagawa²; Harumitsu Suzuki²; Keiko Kondo²; Hiromi Yamauchi²; Takahiro Ito²; Katsuyuki Miura¹ and Hirotsugu Ueshima², (1)Department of Public Health, Shiga University of Medical Science, Otsu, Shiga, Japan, (2)Shiga University of Medical Science, Otsu, Shiga, Japan

Abstract:

Objective: Alcohol drinking has been found to be associated with cognitive decline, dementia and Alzheimer's disease. While studies report decline of cognitive function associated with heavy alcohol consumption, there is still ambiguity with regards to the different drinking status such as light to moderate consumption with this relationship. In addition, there is paucity of knowledge regarding this association among elderly Japanese men. We investigated the association of alcohol drinking status and cognitive score among cognitively intact elderly Japanese men.

Method: On a cross sectional study from Shiga Epidemiological Study of Sub-clinical Atherosclerosis (SESSA), we measured cognitive score of 585 Japanese cognitively intact elderly (≥ 65 years) men who were randomly selected in Kusatsu city using Cognitive Abilities Screening Instrument (CASI) on a scale of 0 to 100. We categorized alcohol drinking status as never, past and current drinker and further categorized the current drinkers according to estimated amount of alcohol consumed as low (<14 g/day), mild ($14 - 23$ g/day), moderate ($>23 - 46$ g/day) and heavy (>46 g/day). The means and adjusted means of CASI score according to the drinking status were estimated by the fractional logistic regression model.

Result: Age, smoking, systolic blood pressure (SBP) and hypertension were significantly different among the different drinking groups. Past drinkers' mean (standard deviation) CASI score was significantly lower compared to never drinkers in unadjusted (Model 1), minimally adjusted (Model 2: adjusted for age and education) and fully adjusted (Model 3: adjusted for Model 2+ Body Mass Index, smoking, exercise, hypertension, diabetes and dyslipidemia) models [Model 1: 87.47(5.25) vs 90.05 (4.90), $p=0.0270$; Model 2: 88.23 (2.59) vs 90.14 (2.22), $p=0.0376$; Model 3: 88.23 (2.59) vs 90.14 (2.22), $p=0.0388$ respectively]. The CASI scores of any subgroup of current drinkers were not statistically different from that of never drinkers.

Conclusion: The CASI score was significantly lower among the past drinkers compared to the never drinkers. Since, current drinkers have the same CASI as never drinkers, our data do not support an association between alcohol drinking amount and cognitive function. However, lower CASI score among the past drinkers may have implications on looking into behavioral changes as an early indicator of future cognitive decline.



PARALLEL SESSION ABSTRACTS

Dementia friendly communities - B

Date: Sunday, 29 July 2018

22-001

HOW RENNES BECAME THE FIRST DEMENTIA FRIENDLY COMMUNITY IN FRANCE IN JUNE 2017 WITH BISTROT MÉMOIRE RENNAIS

Donnio Isabelle*, Bistrot Mémoire Rennais, Rennes, France

Abstract:

Since 2004, in Rennes, Bistrot Memoire welcomes people living with dementia and carers, every week, in a café, sharing good times and conversations. "Living well with dementia" is increasingly a reality thanks to such social innovations. Continuing to change the paradigm of dementia care is the new Bistrot Mémoire's challenge with the implementation of the first Dementia Friendly Community in France since 2017.

The preceding years have been marked by an emphasis on the development of services to rehabilitate people living with dementia. Awareness of the need to re-think the question of Alzheimer with people living with cognitive impairment, from the beginning until the end of their journey, is recent. French public policies are just beginning to be involved in the way of giving a real place and a voice to people living with such disabilities.

We have been impressed by experiences discovered in European countries, such as Foton in Bruges, and EDUCATE and the Stockport dementia strategy. Inspired by meetings and encouraged by EFID, we decided to start the first dementia friendly community in France.

We began to raise awareness cultural partners such as the museums to welcome people living with dementia in 2012. Now we convinced the town mayor of the interest of the project and financiers to give us some means. Since the workshop we organized in Rennes in June 2017, new partners such as restaurants, a fitness club, banks and their employers, schools and high schools joined the project. We also had happenings on Saturday evenings in January 2018, with actors, in the major central places of the town. After interrupting the walk of people in the street to ask for a help in order to find their lost bicycle, or find their ways or the place where they are, or make their lace, both actors and young people living with dementia and volunteers could talk about the situation with passing people who are mostly helpful and kind. After the set up of the first group who raise awareness about dementia, called "the ambassadors", it was the opportunity for people living with dementia to improve their first action. They are now involved to aware waiters in restaurants, coaches in fitness rooms, receptionists in banks.

We actually work with all of the local forces (people directly concerned, professionals, volunteers, in cultural and economics fields ...) to persuade them of the need and the interest to change our image of Alzheimer disease, the importance of a welcoming community. Since two years, people living with dementia take part of our board and active participants in the projects such as the conference organized by the Minister in January about diagnosis and rights.

Thanks to EFID, we had recently the opportunity to share with new European experiences how it's so important to value the expertise of people living with dementia, and we hope the first French initiative will swarm around all over France and join the international movement of awareness.

As Helen Rochford-Brennan says, all these voices matters in order "to move from sadness to advocating for the rights of people living with dementia", the rights to be recognized as a person, still the same person, and the possibility to live well in an inclusive community.



PARALLEL SESSION ABSTRACTS

Dementia friendly communities - B

Date: Sunday, 29 July 2018

22-002

EXPERIENCE OF VILLARICCA NAPLES- ITALY

Patrizia Bruno*, Dementia Center, AMNESIA- Piazza Carlo III 42 - Napoli, Napoli- Villaricca, Italy and Vincenzo Santagada, ordine dei farmacisti Via Toledo 156 Napoli, Napoli, Italy

Abstract:

OBJECTIVES: The city of Villaricca, a small town in the north of Naples, Italy, is building a DFC with the purpose of increasing the knowledge of dementia in citizens and create a comfortable environment for Pwd.

METHODS: Our Meeting Center, that is an open house to all Pwd and their relatives, has made it easier to better understand the process to be followed for a real cultural change. Following the Italian standard, formal and technical procedures, our Community was formalized by the Municipality of Villaricca in a formal agreement and a working table was created. All the stakeholders got together several times to better figure out what needed to be done in order to take citizens and then Pwd on board. After careful consideration of the anthropological, historical and cultural conditions of people from Villaricca, it was found that dementia elapsed completely unnoticed in its earliest and intermediate stages and it was called to the attention of medical professionals only when it was already in its advanced stage and all the therapeutic possibilities were further reduced. Therefore, it has been decided to raise awareness through events like:

1. A public project launch meeting;
2. Training course for traffic officers first, and for all the other workers who are in contact with the public then;
3. A marathon downtown Villaricca through a delimited and visible route, with the involvement of local schools;
4. "Open day" Initiative on 21 September 2018: our house as a community gathering place for all the people, with theatrical and musical performances and cooking classes.

CONCLUSION: The expecting results are: a better involvement of Pwd in local community's activities, starting from a cultural and environmental change; a greater respect for them and for the unavoidable limits connected to this disease, a fight to overcome the social stigma and promote a right education about the problem.

These conditions associated with the starting points will establish a better knowledge of the disease in order for us to discover and address the early stages, give a voice to Pwd and organize our public services the proper way. Furthermore, a supportive and empowering family education will encourage a positive attitude to the problem, a less critical disease's course connected to behaviour disorders, greater management skills and an improvement of the quality of life for Pwd and their families.



PARALLEL SESSION ABSTRACTS

Dementia friendly communities - B

Date: Sunday, 29 July 2018

22-003

FROM FLASHING LIGHTS TO POETRY: FIRST STEPS TO A DEMENTIA-FRIENDLY ROTORUA, NEW ZEALAND

Beth McDougall¹, Bupa New Zealand, Wellington, New Zealand; Rosemary Viskovic, Rotorua Lakes Council, Rotorua, New Zealand; Claire Baker, Bupa New Zealand, Auckland, New Zealand and Lynne Luke, Dementia Lakes, Rotorua, New Zealand

Abstract:

Through raising public awareness, the Dementia-Friendly Rotorua Steering Group increased GP referrals to Dementia Lakes, the local dementia NGO, ten-fold in their first year of action.

'No matter how small the change is, if it helps make life easier for people living with dementia and their care partners, that is a huge step forward', Dementia-Friendly Rotorua Steering Group member.

Rotorua is a city in the middle of the north island of New Zealand. It has a population of approximately 71,700 people. 14.8 percent of people are aged 65 years and over and by 2033 this figure is projected to rise by 80 percent.

Not everyone who has dementia is over 65; however dementia risk increases with age. An estimated 750 people are living with dementia in Rotorua today. With an ageing population it made sense for Rotorua to take action.

In 2016 conversations began between Rotorua Lakes Council and health and care company Bupa. Other interested organisations and individuals, along with a series of public talks indicated clear enthusiasm from the community to make dementia-friendly changes.

In September 2016 the Dementia-Friendly Rotorua Steering Group formed and met for the first time. Now a collective of over 13 organisations and individuals, they work as a team for greater impact.

The Group have created an action plan based on questionnaire responses from people living with dementia, their care partners and the public. The three key focus areas of the action plan are human rights, awareness and services. Achievements include:

- 65 questionnaire responses collected from September – December 2016. 17 percent of responses from people living with dementia





PARALLEL SESSION ABSTRACTS

Awareness

- Affinity, an interactive light sculpture that mimics the effect of dementia on the brain on public display from 2-23 April 2017. Seen by over 6,000 people the sculpture shared sound bites of stories from local people affected by dementia
- First Steps to a Dementia-Friendly Rotorua report published sharing learnings.
- #TurnRotoruaPurple campaign during World Alzheimer's Month. Over 28 businesses turned purple and 10 events took place including:
 - purple teams taking part in the local Ekiden relay race
 - Westpac bank 'keeping your money safe' seminar
- 'Poetry From The Heart' by Michelle Mills, Senior Bupa Caregiver and steering group member. Poems to help people understand dementia shared in newspaper, radio and the library
- Regular visits between a care home and a preschool play group established to encourage intergenerational learning with growing interest

Services

- Alzheimer's New Zealand dementia-friendly awards for four local businesses. Westpac bank, and Bupa Care Homes and Retirement Villages
- Annual dementia-friendly Christmas carol service
- Dovetale Press dementia-friendly classic books available in the library to help people living with dementia to continue the joy of reading

And it's making an impact. Since the work began, GP referrals to Dementia Lakes, the local dementia NGO, have increased ten-fold. This means more people are feeling confident to speak to their GP's about dementia concerns and are being referred to the services they need.

Success is to the credit of the Group members, their passion and dedication. Two key 'ways of working' have been:

- Go where the energy is – Action where there is a need, energy and resource.
- Local and global – Using local knowledge combined with global learnings.

The group have taken their first steps- it's still early days and there's much more to come.





PARALLEL SESSION ABSTRACTS

Dementia friendly communities - B

Date: Sunday, 29 July 2018

22-004

WISCONSIN DEMENTIA RESOURCE NETWORK: BUILDING A DEMENTIA-FRIENDLY STATE THROUGH INNOVATION AND COLLABORATION

Kathleen O'Toole Smith BA; **Kate M Kowalski MSSW**; Sheryl L Coley DrPH and Jane E Mahoney MD, Wisconsin Alzheimer's Institute, Madison, WI

Abstract:

Current estimates indicate that there are approximately 110,000 individuals living with Alzheimer's disease in Wisconsin, with the majority living in the community.¹ By the year 2025, it is estimated that Wisconsin will experience a 14-18% increase in the number of people with Alzheimer's due to increases in the population age 65 and older.² Currently, there are approximately 193,000 unpaid care partners in Wisconsin providing roughly 219 million hours of care for those living with dementia at a cost of \$2.775 billion.³ These figures point to the significant impact Alzheimer's and related dementias have on Wisconsin communities, and this impact will continue to increase.

To address the needs of people living with dementia and their care partners, many Wisconsin communities are working to become dementia-friendly. As the dementia-friendly movement has grown in Wisconsin, many cities and counties have had success in developing promising practices to enhance their dementia-friendly communities and help build dementia-capable organizations. While the number of dementia-friendly communities is growing, there are many areas, both urban and rural, where this movement has not yet begun or is just in its infancy. As a result, discrepancies are evident in the number and quality of dementia best practices, resources, and information available throughout the state.

In 2017, the Wisconsin Alzheimer's Institute (WAI) at the University of Wisconsin School of Medicine and Public Health, building upon its extensive 19-year history of statewide education and outreach, developed the Wisconsin Dementia Resource Network (WDRN) to address this disparity in resources, programs, and information across communities. With the WAI serving as convener, the WDRN is a collaboration of statewide partners working to discover and share innovative best practices, resources and information to help support people with dementia and their families across the 72 counties of Wisconsin. It is the mission of the WDRN to enhance the ability of Wisconsin communities to create supportive and inclusive environments for all people living with dementia. The ultimate goal is to increase awareness, reduce stigma, and increase access to dementia-capable services, leading to earlier diagnosis and better quality of life for people living with dementia and their care partners.

The purpose of this presentation is to describe the development of the WDRN's unique approach, including its programmatic structure, partnerships, product development, and facilitation of community mentorship. Specific attention will be paid to addressing the unique needs of underserved and under-represented groups, both urban and rural, the importance of offering multiple and varied approaches to address the specific needs and resources of each community, funding, and program sustainability.

1 2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association, pg. 21

2 2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association, pg. 22

3 2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association, pg. 39



PARALLEL SESSION ABSTRACTS

Dementia friendly communities - B

Date: Sunday, 29 July 2018

22-006

DAILY LIVING ACTIVITIES WITH RESIDENTS, FAMILIES, AND PEOPLE WITH DEMENTIA IN OUR FRIENDLY COMMUNITIES

Shu-Chun Lee^{*}; Nai-Yu Deng and Jun-Rui Su, Taipei City Hospital, Taipei, Taiwan

Abstract:

Our dementia friendly community is one that lives with its neighbors; one that interacts and shares the feeling of its residents with dementia. It's a place where people with dementia will live companied with residents and families. Where they will be safe and comfortable. Where they will engage in daily activities that we all take for granted. Where the focusing on life in the persons will be understood, and accepted.

Wenshan Community Rehabilitation Center (WsCRC), providing community program for the elderly dementia, is located on the first floor of the Habitat Building in the metropolitan area. In the same building, in addition to our center, there are library, residents' activity center and kindergarten etc. on different floors. Around the building, there are a medical center, two elementary schools, an elderly service center, a village office, and a park in this community. The traffic here is convenient; there are MRT stations and buses can reach the WsCRC.

Our elderly dementia program is open from Monday to Friday, four hours a day. Subjects, who are mild dementia elderly over the age of 50, have a CDR score greater than 0.5. The program mainly provides five services: (1) cognitive promotion and dementia courses; (2) telephone care or home visits; (3) family support groups; (4) caregiver training courses; and (5) surroundings. We serve at least 15 elders with dementia every month. We encourage elders and their families to move out of their houses and enter the community to carry out daily community activities with their residents.

In the fourth quarter of 2017, a total of 22 elderly persons with dementia (50% male) came to our center for community daily activities. We conducted eight cognitive promotion courses with a total of 82 person times, and participants were more than 70% satisfied with the course as a whole. We also provided 19, 16 and 15 telephone interviews in October, November and December respectively to clarify the needs of our clients and our services. Our environment is warm and friendly, elderly people with dementia and their families have expressed their willingness to continue our programs, especially for cognitive promotion activities.





PARALLEL SESSION ABSTRACTS

Dementia friendly communities - B

Date: Sunday, 29 July 2018

22-006

CARER SUPPORT GROUPS AS A STRATEGY IN THE CONSTRUCTION OF PUBLIC POLICIES FOR ALZHEIMER'S DISEASE IN ARGENTINA

Diego Aguilar Velazquez*, Fundacion Leon, Tucuman, Argentina

Abstract:

Faced with the reality of Alzheimer and dementia in North Argentina, Fundación León, as a non-profit ALMA partner, runs support groups, prevention workshops and training for carers in the province of Tucumán since 2009. In 2017, León participated actively in the drafting of Argentina's first provincial law on Alzheimer's disease.

For Tucumán – Argentina's smallest province of over one million inhabitants – Alzheimer's disease is rapidly becoming an important health and social issue. Before 2009, there was a notable lack of organizations that specifically tackled the disease and both patients and carers had very little access to information and support.

The target population of León's programs present at least one indicator of UBN (unsatisfied basic needs). Faced with economic problems, families not only find in León the support they need, but also access to other services and opportunities, through

León poses its programs on a system that has two cornerstones: PSYCHOSOCIAL SUPPORT and ADVOCACY.

We define psychosocial support as the strategy that enables us to approach individuals (patients and carers) in their experience with Alzheimer's disease. In the support process, a professional staff of trained psychologists and social workers run weekly individual interviews and group workshops to develop social skills and to learn more about each personal background. Support implies making a diagnosis of each participant of our programs, designing a work plan and follow up actions.

It is through the support process that we are able to have a comprehensive approach of each family and get to know the needs and reality of Alzheimer's disease in the region. This gives us a special role as a non-profit and enables us to join the conversation on Alzheimer with new material. In 2016-2017, Tucumán legislature invited León to variety of forums, with other speakers: University, physicians and executive government offices. The need of a law was taken into consideration and León participated by contributing with ideas, revising drafts with carers and holding meetings to discuss the law. Finally, legislation was passed on April 2017. It has yet to be regulated.

This presentation aims to transmit the importance and uniqueness of ALMA partners in legislation and policy making in Argentina, and its continuing role in pressuring government to regulate laws in the provincial and national levels.



PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-001

INTERPROFESSIONAL TRAINING AND EDUCATION TO DELIVER PERSON-CENTERED CARE

Mary Guerriero Austrom¹;Dustin Nowaskie²;Carly Carvell³;Mike LaMantia;Sujuan Gao⁵ and Steve Brown⁵, (1)Psychiatry, Indiana Alzheimer Disease Center, Indianapolis, IN, (2)Indiana University School of Medicine, Indianapolis, IN, (3)Family Medicine, Franciscan Health, Indianapolis, IN, (4)Biostatistics, Indiana Alzheimer Disease Center, Indianapolis, IN

Abstract:

Objective: The development of an interprofessional team of health-care workers as part of a CMS Innovation Award, (Dissemination of the Aging Brain Care Program), has proven to be effective in providing person-centered care. Care coordinator assistants (CCAs) were trained in interprofessional teams with a goal of improving health outcomes in community dwelling older adults with dementia and/or depression while providing person-centered care. The purpose of this study was to analyze job satisfaction scores in the CCA team and importance of interprofessional team based care.

Method: 16 CCAs completed the Job Descriptive Index (JDI) as a measure of their satisfaction with work. Additionally, 165 quarterly case reports from CCAs, social workers, and nurses were entered into Nvivo software and content analyzed for themes related to person-centered care and interprofessional teamwork.

Result: Analyses of the JDI indicated that compared to a normative sample of healthcare aids and social workers, the CCAs responded most positively about interaction and dealings with people on their present job; this subscale mean score was higher than the norm. Qualitative analysis of their quarterly case reports indicated that teamwork was a significant positive aspect in providing person-centered care; with emphasis placed on the ability to improve health outcomes in older adults with dementia and/or depression and their caregivers when our interprofessional team worked and trained together.

Conclusion: Interprofessional training with CCAs in a healthcare team to address the needs of community dwelling older adults with dementia and/or depression and their caregivers may provide an effective model of delivering person-centered care to meet the growing demands of this population.





PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-002

DEMENTIA CARE - 4 STARS - FROM NATIONAL GUIDELINES TO IMPLEMENTATION OF PERSON - CENTERED CARE

Dr. Wilhelmina Hoffman*, Swedish Dementia Centre, Stockholm, Sweden

Abstract:

We describe an education in four step, a model in blended learning, to enhance competence using web-based free of charge educations combined with reflection sessions towards implementation of person-centered care in home help service and nursing home care.

Swedish Dementia Centre (SDC) is a non-profit foundation and the government founded national centre for excellence in dementia care. Our commission is to collect, structure and disseminate knowledge into the society and facilitate translation of research into practice. The centre has published several web-educations to various levels in health- and social care, all free of charge and based on the national guidelines.

The SDC was asked to develop a model to enhance competence in dementia care for employees in home help service and nursing home in the city of Stockholm. Stockholm has approximately 900 000 inhabitants living in 14 districts. A pilot project in one district with 98 000 inhabitants was performed during 2016 – 2017. The model demanded close collaboration between SDC and the elderly administration, as well as with the managers of the care units. Step one included the web-education *Dementia ABC*, approved test and three hours reflection about the ten chapters. *Dementia ABC plus home help service* or *Dementia ABC plus nursing home* was the second step. The same procedure as in step one then followed. The third step was learning how to use *The checklist* for home help or nursing home care. This tool enables to control that the guidelines for each person is followed. Using the checklists, the managers were encouraged to document in the Swedish dementia quality registry *SveDem*. The fourth step was to learn about how avoiding restraints from the web-education *Vision Zero*, test and reflection followed. This enabled the managers to introduce a Vision Zero policy at their unit. The results of the pilot will be presented.

The second step will also be introduced and describes how star instructors are trained to become local teachers around the country. The stars are provided from SDC if 80% of the working force has succeeded the education in four step. The stars are valid for one year. The leader of the care unit is responsible to report to the star instructor who, in turn, report to SDC if the stars should be given for the next year. New employees are continuously educated by the star instructors.

This model of blended learning in dementia care provides a possibility for a national overview of basic knowledge in dementia care. The model is also cost effective when performed with free of charge national web-educations and by local trainers.



PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-003

DEMENTIA TRAINING FOR HOMECARE PROVIDERS

Raj Kapoor Mr*, Commercial Intelligence And Outreach, Alzheimer's Society UK, London, United Kingdom

Abstract:

As the number of people living at home with long term, often complex conditions increases, homecare workers are being asked to take on challenging tasks on a daily basis, in a lone role often under severe time constraints. The working environment in which they operate is unlike any other, and it is vital that quality training exists to ensure homecare workers are well equipped to carry out their role. The research also suggests at least 250,000 homecare workers are providing care for someone with some form of dementia.

More than 1/3 people living with dementia receive personal care from homecare workers, with providers estimating 60% of people using their service have some form of dementia (many of whom have not received a formal diagnosis).

A recent Unison (Feb, 2016) survey found 27% of homecare workers had no dementia training whatsoever and 52% of those who had did not believe it was good enough for their role.

The training programme would help to deliver key aims of The Prime Minister's Challenge on Dementia 2020, which stated:

- 'There should be greater recognition by commissioners across health and care services of the value of homecare services, both for those that receive them and in reducing more costly crisis care.'
- 'By 2020 we would wish to see increased numbers of people with dementia being able to live longer in their own homes when it is in their interests to do so, with a greater focus on independent living.'

To address the above need Alzheimer's Society has developed a one day Train the trainer programme for homecare workers.

The programme is made up of three core components:

- **One day "train the trainer" workshop** – The workshop is designed to equip trainers and managers of homecare agencies with the information, techniques and support resources to enable them to deliver effective dementia training to front line care teams within their organisations.
- **Resource pack** – The resource pack provides the lesson plans, guidance, workbooks and other materials to support trainers and managers in designing and delivering training within their organisations.
- **Onward training of frontline care teams** – A modular programme totaling 10 hours of training per member of front line care staff will be run within provider organisations by the trainers who have attended the one day workshops, using the guidance and support materials included in the Resource Pack.

The programme content is organised in line with NHS England's transformation framework "The well pathway for dementia" and is structured around the following five themes:

- Diagnosing well
- Preventing well
- Living well
- Dying well
- Supporting well



PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-004

DEVELOPING LEADERSHIP IN DEMENTIA PRACTICE - THE DEMENTIA CHANGE CHAMPIONS APPROACH

Jason Burton*, Alzheimer's WA, Perth, WA, Australia

Abstract:

A growing recognition of the need to focus dementia training and workforce development on the “adoption” and “adherence” end of the knowledge translation scale has seen a new and innovative approach to workforce development developed in West Australia with the aged and health care sector. In partnership with the WA Government, and in response to a self identified need by the aged care service sector, Alzheimer's WA has developed a Dementia Change Champion program to address a disconnect that exists between staff undertaking training and translating this new knowledge into practice. The program is designed to create dementia specialist practice leaders and change agents in dementia care who become a learning and practice development resource for their care environment or organisation. The Dementia Change Champions role is to be a driver of practice change and the organisation's “go to” resource for information, education and dementia development. The program has been successfully implemented in community and hospital organisations in metropolitan and regional West Australia over the last 4 years and has recently undergone an independent evaluation.

Over 100 Champions have graduated since the inception of the program in 30 aged care organisations and 10 hospitals making this the largest capacity building program of its type in Australia. Unique features of this program include the requirement of the organisation to commit to supporting the Champion role, development of action plans, an intensive training and mentorship program for the Champion, an alumni providing the Champion with a broad network of support and learning, ongoing support and mentorship from the program, online network and learning opportunities, an ongoing registration requirement to remain a Champion and a strong train the trainer model that equips the Champion to fulfill their role as a practice leader in dementia care in their organisation.

As a capacity building model this program is flexible in its adaptation to different environments and needs and has been successfully adapted to supporting organisations who provide services to Australian Culturally and Linguistically Diverse (CaLD) communities.

This presentation will explain the Champions development pathway, share findings from a recent independent research study of the programs outcomes and share case studies of how the Champions are changing practice in their services.



PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-005

TRANSFORMING DEMENTIA PRACTICE THROUGH A PARTNERSHIP APPROACH

Caroline Horlock, Education & Consultancy, Alzheimer's WA, Perth, Australia

Abstract:

It is over 25 years since Tom Kitwood first began sharing with the world his exploration of person centred care and a new understanding of the lived experience of a person with dementia. 25 years on, and despite a myriad of training and dementia education programs, there remains a significant gap between philosophy and practice in many care environments.

Creating sustainable culture change from task and medical dementia paradigms to person centered wellness models, with a focus on improving the lived experience of dementia remains one of aged care services greatest challenges

Alzheimer's WA has developed a new innovative model to bridging this gap that creates sustained culture and practice change in dementia care services.

In 2013 a partnership between the West Australian Government and Alzheimer's WA was formed to develop a range of new innovative approaches to supporting sector wide development, increase dementia knowledge and skills of staff, introduce person centered approaches to community services and provide a range of learning resources and consultation services. Based around the concepts of adult learning, change management and knowledge translation, this effective suite of dementia specialist training approaches to changing practice has shown positive outcomes for improving practice.

The Dementia Partnership Project has collaborated with over 50 community organisations in West Australia in the last 4 years and has shown to have had significant impact in transforming community services approaches to dementia care. This presentation will share the findings of a recently completed external evaluation of the program by Professor Wendy Moyle at Queensland University of Technology and explore the learnings from the last 4 years on supporting adoption and adherence of practice change in community care organisations.





PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-006

WHAT WORKS IN DEMENTIA EDUCATION AND TRAINING?

Sahdia Parveen^{*1}; Jan R Oyeboode²; Cara Sass³; Michelle Drury⁴; Natasha Burnley³; Sarah Smith³; Alison Dennison² and Claire Surr³, (1)Centre for applied dementia studies, University of Bradford, Bradford, United Kingdom, (2) University of Bradford, Bradford, United Kingdom, (3)Leeds Beckett University, Leeds, United Kingdom, (4) University of Leeds, Leeds, United Kingdom

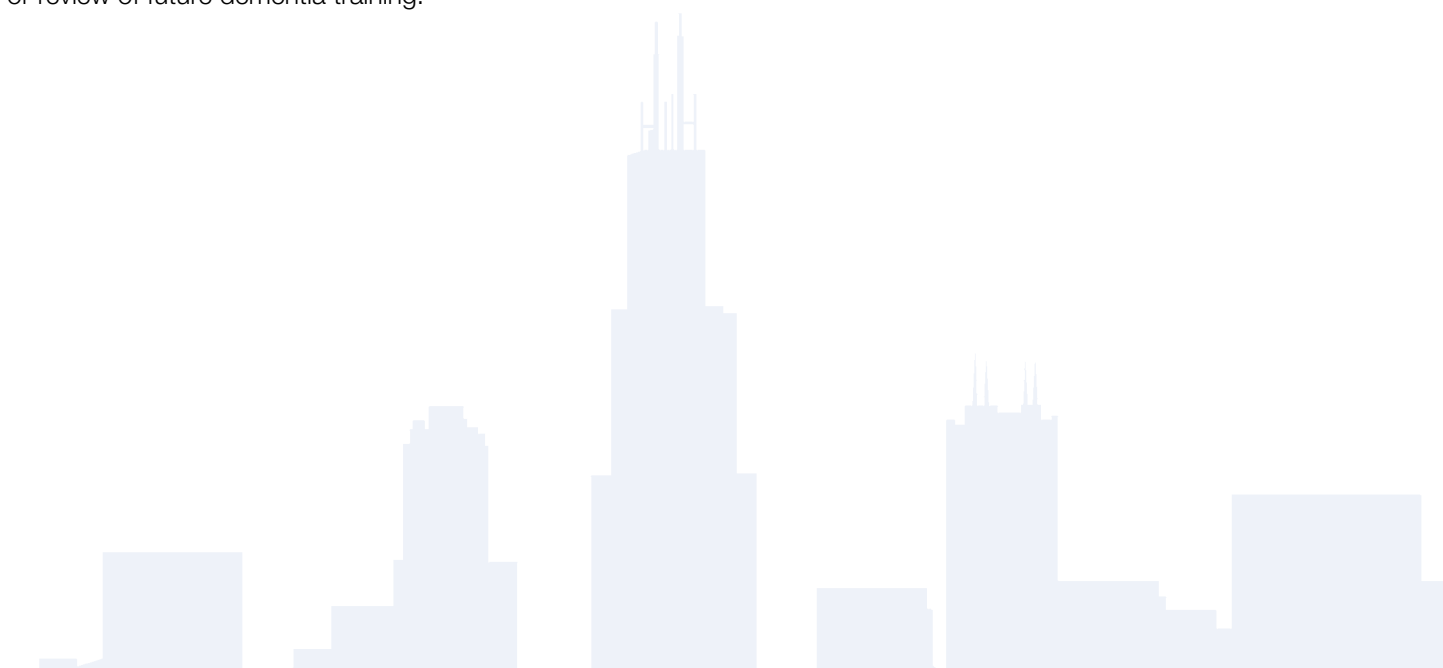
Abstract:

Objective: The need for an effective and knowledgeable dementia workforce is of international concern. However, the dementia workforce is diverse and its educational needs are complex, making it difficult to identify what components of education and training are effective. Previous research has found that dementia education and training can improve staff knowledge and confidence and thus have a positive impact on the lives of people living with dementia and their families. The aim of this UK-based national evaluation of dementia education and training was to identify what constitutes effective dementia education and training for the dementia workforce.

Method: This study used a range of methods including: a systematic review of the dementia education and training literature (work package one), a national audit of the dementia education and training available, a staff survey of knowledge, attitudes and self-confidence (work package 2) and ten case studies (work package 3). The case studies were conducted across mental health trusts, acute care, primary care and care homes and involved 13 different methods of data collection. The evaluation was underpinned by input from an expert-by-experience group who contributed to study design, conduct, analysis of data and outputs.

Result: A number of key ingredients for successful dementia education and training emerged across the three work packages. Training was better received and more impactful when it was relevant to staff roles, covered fewer subject areas, was underpinned by practice based learning and involved interactive learning through activities or simulation. Training delivered by an experienced trainer in small face to face groups was the most successful.

Conclusion: The findings have implications for the design and delivery of dementia education and training and of relevance to care providers, training providers and commissioners, when considering purchase, development or review of future dementia training.





PARALLEL SESSION ABSTRACTS

Education and training of the workforce

Date: Sunday, 29 July 2018

23-007

DETERMINANTS OF INTENTION AMONG PRIMARY CARE PHYSICIANS IN PUERTO RICO TO MAKE AN EARLY DIAGNOSIS OF ALZHEIMER'S DISEASE: AN APPLICATION OF THE THEORY OF PLANNED BEHAVIOR

Mirna L Arroyo-Miranda DrPH¹; Jessica Irizarry-Ramos PhD²; Ernesto Rosario-Hernandez PhD³ and Ms. Lilliam J Valcarcel MSW¹, (1)Public Health Program, Ponce Health Sciences University, Ponce, Puerto Rico, (2) Public Health Program, Ponce Health Sciences University, Ponce, PR, Puerto Rico, (3)Psychology and Brain Sciences, Ponce Health Sciences University, Ponce, PR, Puerto Rico

Abstract:

Objective: Alzheimer's disease (AD) is the fourth leading cause of death in Puerto Rico (PR), yet it is highly underdiagnosed and undertreated. It is estimated that about 50% of all cases are diagnosed. From the time patient arrives with first symptoms of AD, it can take up to 2 years to be diagnosed. Reasons for this delay may be related to beliefs of physicians about AD. Efforts in PR to educate primary care physicians (PCPs) on AD have not been guided by scientific studies that identify the causes for the lack of diagnosis. If affective factors of underdiagnosis are not addressed, efforts to improve early diagnosis of AD will not be effective. There are no studies in Puerto Rico about the attitudes of PCPs towards AD and, to our best knowledge, there are no studies that address the problem from the Theory of Planned Behavior (TPB) framework.

The present study addressed barriers and limitations of PCPs to make an early diagnosis of AD, using the framework of the Theory of Planned Behavior. TPB is a simple-construct health model often used to explain behaviors of health professionals. The study aimed to determine: (a) intention of PCPs to perform an early diagnosis of AD; (b) association between theoretical constructs (attitude, subjective norm and perceived behavioral control) and intention of PCPs to perform an early diagnosis; and (c) if salient beliefs under each construct hinder or promote PCPs' intention to perform an early diagnosis of AD. We defined early diagnosis as "performing the recommended clinical testing to make an exclusion diagnosis of Alzheimer's disease within three months from the patient's first complaint."

Method: This study was quantitative and cross-sectional in nature. We designed a questionnaire to measure each construct directly and indirectly to elicit salient beliefs related to each construct. Final sample size was 103 participants, assessed either online or through paper-based questionnaire. Validity and reliability measures were assessed and structural equation analysis conducted using PLS-SEM (SmartPLS, 3.0).

Result: Attitudes, Subjective Norm and Perceived Behavioral Control (PBC) constructs in both the direct and indirect models reached validity and reliability standards ($\alpha \geq .70$, Composite Reliability $\geq .70$, AVE $\geq .50$). Direct structural model reached predictive relevance of .268. Combined, the three constructs in our direct model explained 35.7% of the variance, reflecting a strong intention of PCPs to perform an early diagnosis of AD ($R^2 = .357$, $p < .001$). PBC was the strongest predictor of intention, which suggests that training, combined with years of experience are key to having a positive outlook for early diagnosis ($b = .378$, $p < .001$). Items remaining in the indirect model support findings of the direct model; most salient beliefs in all constructs were significantly correlated to amount of training hours in AD management and years of experience.

Conclusion: TPB is a good model to examine intention to make an early diagnosis of AD. Our findings could be of use to design interventions to improve PCPs diagnosis practices and dispel myths about AD. Training by modeling is key to changing PCPs' Perceived Behavioral Control and subsequent behavior. Data on attitudes and practices of PCPs regarding diagnosis and management of AD could also be useful to patient associations for advocacy purposes.



PARALLEL SESSION ABSTRACTS

Psychosocial interventions

Date: Sunday, 29 July 2018

24-001

AUTO ETHNOGRAPHY: AN INTERVENTION FOR DEMENTIA

Kate Swaffer Ms^{*}, University of Wollongong, Wollongong, Australia

Abstract:

The purpose of this presentation is to present autoethnography (AE) as a new and unique psychosocial intervention for dementia. It will discuss this not only as an approach to more fully understand the lived experience of dementia, but as a method of therapeutic healing following a diagnosis of dementia. It is an ethical exploratory research approach and practice, which so far has been found to be an investigative method, which engages with the theory of AE, with the express purpose of understanding if there is utility and value in this methodology for the understanding, more deeply, of the lived experience of dementia. An initial examination of autoethnography as a psychosocial intervention suggests that autoethnographic writing practice is affective, critical and extremely informative and informative, and holds the possibility of a new way to help create change in nursing practice. Creating improved quality of life and well being and providing a new use of narrative that health care professionals can use, as an intervention for dementia is critical to change. Investigating the deeper understanding of the lived experience of dementia through autoethnography, this presentation also elucidates a greater ethical understanding of whose story the lived experience of dementia is to share. I will also discuss this relatively new methodology and its use in not only exploring more genuinely the lived experience of dementia, and my presence inside that domain most others define as a critical illness, but how it fits within the spectrum of disability. Finally, through the lens of autoethnography, I will discuss the value of self-advocacy, self-help and peer-to-peer support, in terms of a more positive response to a critical illness, and if this methodology is of real value to people diagnosed with any type of dementia.





PARALLEL SESSION ABSTRACTS

Psychosocial interventions

Date: Sunday, 29 July 2018

24-002

APPLICATION OF THE COGNITIVE STIMULATION THERAPY FOR DEMENTIA PATIENTS IN CHINA

Zhaorui Liu*; Hongguang Chen; Yueqin Huang; Chao Ma; Xiao Wang; Rui Shen; Minghui Li and Mengqian Li, Institute of Mental Health, Peking University, Beijing, China

Abstract:

Objective: This study is to evaluate the effect of Cognitive Stimulation Therapy (CST) among mild or moderate dementia patients in China.

Methods: A single blind randomized clinical trial was carried out in Beijing China from 2014 to 2016 among dementia patients in early or mild stage. Patients were divided into the intervention group and control group using a stratified randomized sampling strategy based on the severity of dementia. The intervention group received CST for seven weeks, while the control group received treatment as usual (TAU). The carers of those in the intervention group also received the 'Helping Carers to Care' intervention for five weeks. Outcome evaluations were conducted at baseline, three weeks, seven weeks, and three months. In addition to the quantitative evaluation of the intervention, qualitative interviews were conducted with a sample of patients and their caregivers to gather feedback on their experience of CST.

Results: Preliminary findings suggest evidence of delayed deterioration of cognitive function during CST. Caregiver strain also decreased in carers of those receiving CST. However, at the three month follow-up, these improvements were not detected. In the qualitative study, many carers reported they thought CST could be used to prevent cognitive impairment, and taking part in similar stimulating activities might be beneficial for their own memory problems. They learned ways to communicate more effectively with the patients. Carers also suggested that the research group should carry out CST in the community, rather than in hospitals, which they felt would be more convenient. Most carers and patients were satisfied with the arrangement of the CST sessions, and they said they felt very happy after finishing them. Indeed they said they would like to attend more, if further CST sessions were provided.

Conclusion: The findings of the trial suggest the current Chinese version CST is effective during the treatment period, and it is feasible and acceptable. However, our findings show the seven-week duration of treatment may not be enough to maintain cognitive benefits, and as such more sessions may be required.





PARALLEL SESSION ABSTRACTS

Psychosocial interventions

Date: Sunday, 29 July 2018

24-003

COMMUNITY BASED OCCUPATIONAL THERAPY FOR PEOPLE WITH DEMENTIA (COTID) AND THEIR CAREGIVERS: EVIDENCE FOR APPLICABILITY IN ITALY

Andrea Fabbo¹; Petra Bevilacqua²; Lucia Bergamini³; Alessandro Lanzoni⁴; Glenda Garzetta²; Sara Barbieri⁵; Elena Lucchi⁶; Alessandro Morandi⁶; Christian Pozzi⁶ and Maud Graff⁷, (1)Cognitive Disorders and Dementia Unit, Local Agency for Health of Modena, Modena, Italy, (2)ASDAM Association Mirandola, Mirandola, Italy, (3)Cognitive Disorders and Dementia Unit, Local Agency for Health of Modena, Mirandola, Italy, (4)Asdam Association Mirandola, Mirandola, Italy, (5)Rehabilitation Medicine, Local Agency for Health of Modena, Mirandola, Italy, (6) Teresa Camplani Foundation Ancelle della Carità, Cremona, Italy, (7)Radboud University Nijmegen, HB Nijmegen, Netherlands

Abstract:

Objective: to determine the applicability in the Italian country of community based occupational therapy on occupational performance and satisfaction of people with dementia (PWD) and the sense of competence of their care givers (CG).

Method: this is a prospective study that included 27 people with mild to moderate dementia and their caregivers in the setting of a Memory clinic and day clinic of a geriatrics department and participants' homes in the district of Modena and Cremona, both from private and public services. We included in the study 27 patients aged with mild to moderate dementia living in the community and their primary care givers. Mean age of the population was 80,59 (47 – 91) for people with dementia and 57,78 (22-84) for caregivers. The majority of caregivers were sons of the people with dementia. The interventions consisted of 10 sessions of occupational therapy over five weeks, as the original dutch program. Main outcome measures level of performance and satisfaction during the participation in significant activities perceived by people with dementia assessed with Canadian Occupational Performance Measure (COPM). Care giver burden assessed with the sense of competence questionnaire (SCQ). Participants were evaluated at baseline and at the end of the treatment.

Result: gathered data were analyzed. Results showed a significant improvement at SCQ by caregivers (77,19 +/- 13,27 pre) (82,56 +/- 12,57 post) $t=-3,102$ $p=.005$. People with dementia showed significant improvement in COPM performance (4,56 +/- 1,44 pre) (6,68 +/- 1.59 post) $t=-6.597$ $p=.000$ and COPM satisfaction (5,08 +/- 1,84 pre) (7,04 +/- 1.71 post) $t=-6.180$ $p=.000$. Non significant variations were registered in the cognitive functioning (MMSE), behavioral and psychological symptoms of dementia (NPI), daily functioning (DAD), depression (GDS), perceived quality of life (QOLAD) and global health (SF-12) of people with dementia. Neither for caregivers were found evidence of significant variations in domains of quality of life (QOLAD), global health (SF-12, GHQ), depression (CES-D) or burden (Zarit).

Conclusion: COTiD program is applicable in Italy and results are promising for it's implementation at a national level. Further studies are needed to explore effects on follow-up.



PARALLEL SESSION ABSTRACTS

Psychosocial interventions

Date: Sunday, 29 July 2018

24-004

EXPLORATION OF THE ROLE OF ACTIVITIES AND IMPLEMENTATION OF MEANINGFUL ACTIVITIES TO SUPPORT PATIENTS WITH DEMENTIA DURING AN ACUTE HOSPITAL STAY

Monika Rybacka^{*}, Dementia Care, University of the West of London, London, United Kingdom and Joanne Mary Brooke Dr, OxIMNAHR, Oxford Brookes University, Oxford, United Kingdom

Abstract:

Objectives: The negative impact of a hospital stay on a person with dementia includes a decline in pre-admission physical, mental and cognitive abilities (Dewing and Dijk 2014). In acute hospital settings activity coordinators and meaningful activities for patients with dementia are being developed and implemented to support their social relationships, physical activity, and sustain physical and mental health (Jennings 2006). However, there is currently no overview of the impact of these initiatives on patient outcomes. The aim of this study was to explore the impact of activities provided by activity co-ordinators during an acute hospital stay, with the specific objectives of how staff and relatives view the impact on the person with dementia and how the activity co-ordinators develop activities based on individual needs.

Methods: A sequential mixed methods design within an inductive interpretative phenomenological approach was applied. Activity co-ordinators, based on general medicine wards within a busy acute hospital routinely completed a standardised audit following each interaction with a patient with dementia, providing information on: number of interactions, activities completed and an observed impact on the patient. A survey with open questions was completed by staff, relatives and visitors regarding their perceptions of the: role of the activity co-ordinators, interactions and impact on the patient with dementia. Data was collated and a thematic analysis as described by Braun and Clarke (2006) was completed.

Results: During eight months of data collection the activity co-ordinator provided activities for 189 patients, of which 80 had a diagnosis of dementia. A total of 27 questionnaires were completed (staff n=22, relative n=4, visitor n=1) between July-December 2017 within a large NHS Foundation Hospital in England. Two overarching themes emerged from the analysis: firstly, 'reduction in boredom through stimulation', relatives, visitors and staff agreed the activities engaged patients with dementia reducing their boredom with activities that were fun and provided warmth and enjoyment. Secondly, 'a positive impact on patient's with dementia', staff reported an improvement in patient's sleeping patterns, nutritional intake, and the belief that patients were more engaged with staff and had less falls.

Conclusions: The data emphasized a positive impact of the employment of activity co-ordinators within an acute hospital, to provide support for patients with dementia. The activities focused on music and art as subjects for patients to engage with and the activities were person-centred taking into consideration the needs and the abilities of the patient. Both staff and relatives/visitors agreed the new focus on increasing stimulation and reducing boredom was beneficial for the patient. The study only focused on music and art activities within the acute setting, further exploration is required in regards to the specific activities and whether activities were meaningful or simply enjoyable.

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PARALLEL SESSION ABSTRACTS

Psychosocial interventions

Date: Sunday, 29 July 2018

24-005

PROMOTING INDEPENDENCE IN DEMENTIA (PRIDE) A FEASIBILITY STUDY OF A PSYCHOSOCIAL INTERVENTION IN MILD DEMENTIA

Emese Csipke Dr^{*1};Phuong Leung Dr¹;Lauren Yates Dr²;Holly Walton Ms¹;Linda Birt Dr³ and Martin Orrell Prof², (1)University College London, London, United Kingdom, (2)Division of Psychiatry and Applied Psychology, University of Nottingham, Nottingham, United Kingdom, (3)University of East Anglia, Norwich, United Kingdom

Abstract:

Objective: Dementia often leads to social exclusion, loss of identity and independence. This is in some cases due to deterioration in cognition and activities of daily living. The double stigma of age and dementia, and the resulting reduced capacity for social participation. The aim of the study is to investigate the feasibility of the Promoting Independence in Dementia (PRIDE) psychosocial intervention delivered by dementia advisors (DA's) to persons with dementia and their supporters. This study aims to: 1) establish and field test the PRIDE intervention; 2) assess DAs fidelity in delivering of the intervention and engagement with people with dementia; 3) assess the feasibility and acceptability of outcome measure data and 4) assess the acceptability of the intervention by stakeholders.

Method: A psychosocial intervention was developed based on the Medical Research Council (MRC) framework for the development and evaluation of complex interventions. People with mild dementia were recruited across England. DAs from health, social care, or the voluntary sector working in or alongside memory clinics, were recruited and trained to deliver the three session intervention, which was delivered as a paper manual. Quantitative outcome measures were taken at baseline and followed up by up to three months post baseline. Fifteen questionnaires were administered for persons with dementia, with the Bristol Activities of Daily Living being the main outcome measure. Supporters completed three questionnaires. Fidelity checklists were utilised to assess fidelity to the intervention, completed by both dyad taking part and the DAs. Qualitative post-intervention semi-structured interviews with staff and focus groups with participants were conducted. This included data to examine participant experiences of and engagement with the intervention, and other aspects of delivery such as recruitment of DAs, fidelity and experiences receiving and delivering the intervention.

Result: Thirty four participants and their supporters were recruited to take part in the trial. Thirty two percent (n=23) were women, and the average age was 77.50 (SD 8.69); 71% (n=26) of supporters were women with an average age of 69.42 (SD 12.03). Ninety seven percent (n=33) of persons with dementia White, and three percent (n=1) was Asian British. Seventeen (53%) were diagnosed with Alzheimer's type dementia, three (9%) with vascular, and 12 with mixed or unknown diagnosis. Initial analysis of the quantitative data indicate that participants did not have trouble completing the measures and missing data was at a minimum, and the return rate fidelity checklists was high. Qualitative data indicated that participants valued the intervention, in particular the interaction with the DAs.

Conclusion: Initial analyses indicate that the intervention was welcomed by the persons with dementia and their carers, and DAs had positive views of the delivery of the intervention. The study however did find that the coordination of sites taking part with the availability of DAs was a challenge. The results of this feasibility study will allow us to plan for a definitive RCT of a three session dementia advisor led intervention for mild dementia and we look forward to presenting final results.



PARALLEL SESSION ABSTRACTS

Environment and technology

Date: Sunday, 29 July 2018

25-001

FAMTECHCARE: A TELEHEALTH INTERVENTION LINKING DEMENTIA CARE EXPERTS WITH CAREGIVERS OF PEOPLE WITH DEMENTIA

Dr. Diane Blyler¹; Kristine Williams²; Claire Shaw³; Elena Perkhounkova⁴; Maria Hein³; Denise Seabold¹; Eric Vidoni⁵ and JoEllen Wurth⁵, (1)College of Nursing, University of Iowa, Iowa City, IA, (2)University of Kansas, Kansas City, (3)The University of Iowa, Iowa City, (4)Office of Nursing Research and Scholarship, University of Iowa, Iowa City, IA, (5)Alzheimer's Disease Center, University of Kansas, Fairway, KS

Abstract:

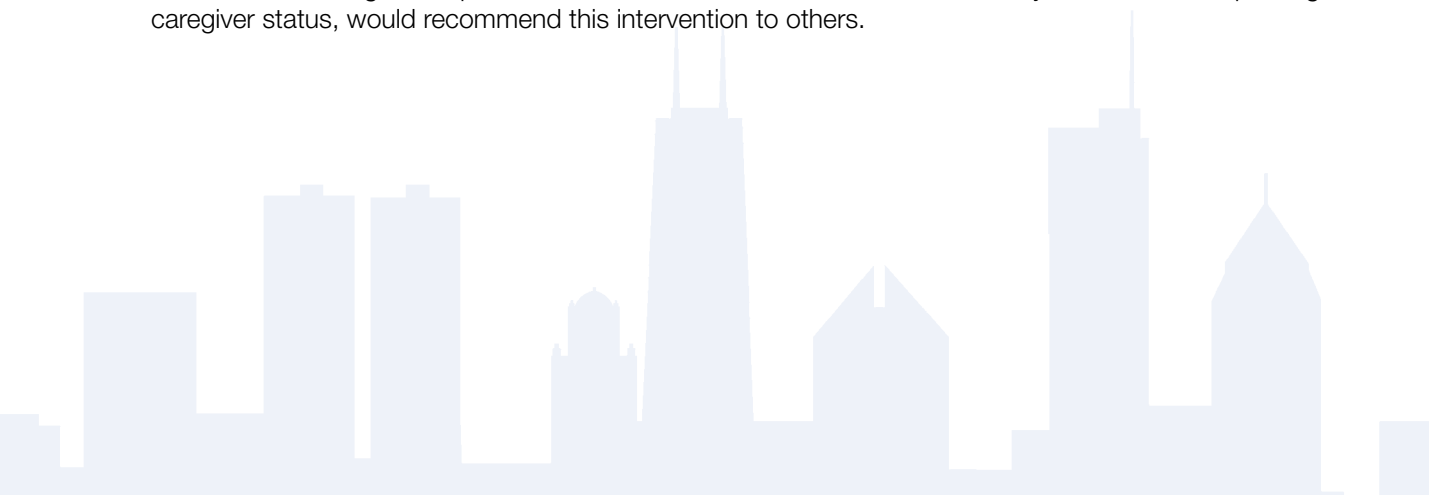
Objective: The FamTechCare study is a clinical trial to assess the effectiveness of a telehealth intervention for everyday care situations for caregivers of people living with dementia. An AARP study (2016) found that 78% of caregivers report being interested in technology to support their caregiving tasks but only 7% are using technology that is available to them.

This presentation will discuss caregiver satisfaction with a home monitoring unit and whether factors such as disease severity or individual caregiver characteristics such as age or family relationship are significantly related to satisfaction with home monitoring.

Method: Study participants submitted videos using Behavior Connect, a HIPAA-secure application, on an iPad. The Satisfaction with Home Monitoring measure is an 11-item instrument with a 5-point scale (1 = strongly disagree to 5 = strongly agree). Participants in both the intervention and control groups completed this measure at the end of the study. Intervention participants received feedback each week on videos; control participants received feedback on videos at the end of the study. Each family, regardless of treatment condition, received a weekly call to discuss care issues.

Result: Of the 57 caregivers (34 spouses, 13 children/spouses of children, and 10 'other') who completed this measure, 96% reported having the unit in the home was acceptable, 93% reported the training to use it was helpful, 77% reported easy to transfer recordings to the internet, 72% reported it was easy to set up and use, and 75% indicated ideas to change the behaviors were helpful. Only 12% indicated preference for a home visit. Spouses and those in the "other" category found care suggestions were effective compared with children/spouses of children ($p = .01$). There were no significant differences by caregiver age. More severe dementia was significantly associated with caregivers who reported the care suggestions were effective and helpful ($p = .02$). There was no significant relationship between stage of dementia and preference for a home visit, suggesting the intervention was helpful regardless of disease severity.

Conclusion: Caregivers reported benefit from the telehealth intervention. Fully 97% of the sample, regardless of caregiver status, would recommend this intervention to others.





PARALLEL SESSION ABSTRACTS

Environment and technology

Date: Sunday, 29 July 2018

25-002

THE USE OF TECHNOLOGY IN DEMENTIA FAMILY CAREGIVING IN RURAL MICHIGAN OF THE UNITED STATES: BARRIERS AND STRATEGIES

Fei Sun¹, School of Social Work, Michigan State University, East Lansing, MI; Zhenmei Zhang², Sociology, Michigan State University, East Lansing, MI; Emmanuel Chima, Michigan State University, East Lansing and Brenda Roberts, None, Elwell, MI

Abstract:

Objective: Technology can be used to deliver treatment and services to dementia patients, assist family caregivers with monitoring patient safety and behavioral problems, and facilitate social connection and resource access for both patients and family caregivers. Access to caregiving resources through technology (e.g., tablet, Internet, social media) can be particularly crucial for rural family caregivers given the lack of resources in local communities and access difficulties. This project focuses on examining the role of technology in dementia family care in rural areas of Michigan in the U.S. The specific aims are: 1) to understand the challenges faced by dementia family caregivers in rural Michigan; 2) to learn about the role of concrete technology means in addressing needs of rural family caregivers; and 3) to identify strategies to improve resource access through building technology competency in rural family caregivers.

Method: Data from this study came from two sources: survey and focus groups. Secondary survey data were drawn from the Michigan Dementia Coalition online survey of 1,506 individuals from 75 out of 83 counties in Michigan. More than two thirds are rural counties; about 25% are family caregivers who currently provide care to a relative with dementia. Content analyses were performed on 791 answers to one open-ended question on perceived service needs for dementia families in Michigan. Additionally, first hand data were collected through focus groups. One focus group with four rural family caregivers and the other with four service professionals were run to solicit their perspectives of the role of technology use in meeting rural caregiver needs. Interviews were recorded, transcribed and analyzed for themes emerging from focus group discussion.

Result: Survey data suggest that the overarching challenges faced by rural dementia family caregivers centered on lack of informal and formal support. Specifically, limited financial resources, the unavailability of adult children, lack of medical specialists, and limited supportive services all exacerbate caregiver stress, which takes a toll on their health, particularly for senior caregivers. Technology used in family dementia care included assisting caregiving tasks (e.g., monitoring a wandering care recipient), facilitating treatment (e.g., access treatment through telemedicine), and providing social connection and support for family caregivers. Themes related to strategies to facilitate resource access included addressing educational needs of young older and old-older caregivers, providing step-by-step toolkits, collaborating with various sectors such as public libraries, grocery stores, and churches in service delivery.

Conclusion: Findings of this project, although preliminary, provide evidence that is potential useful to create an intervention to improve technology use in dementia family caregiving. Suggestions for rural service providers are to partner with community sectors (e.g., business, church), and to seek innovative ways to use technology to deliver their treatment and services. However, the strength of rural communities---the strong sense of community among residents due to mutual trust and support should not be ignored. Technology provides a way to connect rural families affected by dementia connected to the larger society.



PARALLEL SESSION ABSTRACTS

Environment and technology

Date: Sunday, 29 July 2018

25-002

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PARALLEL SESSION ABSTRACTS

Environment and technology

Date: Sunday, 29 July 2018

25-003

KINECT BOWLING: IMPLEMENTING MOTION-BASED TECHNOLOGIES FOR PEOPLE WITH DEMENTIA

Arlene J. Astell, Psychology & Clinical Language Sciences, University of Reading, Reading, United Kingdom and **Erica Dove***, Research & Academics, Ontario Shores Centre for Mental Health Sciences, Whitby, ON, Canada

Abstract:

Objective: Xbox Kinect is a games system utilising motion-based technology. Such systems can provide cognitive, physical and social benefits for people with dementia (Dove & Astell, 2017a). However, there has been a lack of investigation of how to introduce, teach and support people with dementia to use this type of technology (Dove & Astell, 2017b). This study set out to examine the implementation of motion-based technology (Xbox Kinect) as a group activity for people with dementia in day programs.

Method: The study was conducted in a community-based adult day program for people with dementia and other age-related challenges. Participants with dementia (n=11; mean age=77.73 years; mean Montreal Cognitive Assessment (MoCA; /30) =15.36) were invited to play a digital bowling game on an Xbox Kinect twice a week (1 hour per session) for 12 weeks (i.e. 24 sessions). The sessions were led by a member of the research team using techniques identified from a review of the literature relating to motion-based technology use for people with dementia. These techniques included task breakdown, gesture modelling, verbal reminders and immediate error correction. Data were collected in the form of video recordings of each hour long group session to capture a comprehensive view of the participants, the trainer, the environment and the activity. Video recordings were analyzed using behavioral coding software, to isolate and track aspects such as the amount and type(s) of assistance provided to participants by the trainer, the duration of participants' turns, and participants' ability to complete turns independently versus with support. Video recordings were compared pre-post and analyzed using a paired t-test. The videos also provide information about the impact on participants of being in the Kinect bowling group.

Result: The findings revealed that people with dementia can learn to play games presented on Xbox Kinect with repeated exposure and appropriate training. This was evident through a reduced need for assistance from the trainer ($p<.01$), shorter duration of turns ($p<.01$) and greater amount of independent play by the end of the 24 sessions ($p=.007$). The findings demonstrate that people with dementia can learn and continue new behaviour which challenges negative stereotypes about their abilities. Upon completion of the study, the day program purchased an Xbox Kinect which they are now using as a regularly-scheduled group activity.

Conclusion: This study highlights the potential benefits and feasibility of implementing motion-based technologies such as the Xbox Kinect into community-based adult day programs for people with dementia.

References:

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PARALLEL SESSION ABSTRACTS

Environment and technology

Date: Sunday, 29 July 2018

25-004

WHAT HAVE WE LEARNED? SYSTEMATIC REVIEW OF THE IMPLEMENTATION OF E-HEALTH INTERVENTIONS FOR INFORMAL CAREGIVERS OF PEOPLE WITH DEMENTIA

Hannah Christie¹; Ms. Sara Laureen Bartels²; Lizzy Boots³; Huibert Tange³; Frans Verhey³ and Marjolein E de Vugt³, (1)MHeNS, Maastricht University, Maastricht, Netherlands, (2)Department of Psychiatry and Neuropsychology, Maastricht University, Maastricht, Netherlands, (3)Maastricht University, Maastricht, Netherlands

Abstract:

Objective: E-health research has provided many innovative and effective interventions with the potential to meet the support needs of informal caregivers of people with dementia. However, little is known about which factors determine their successful implementation. Therefore, the aims of this study were to (1) systematically review the literature on the implementation of E-health interventions for informal caregivers of people with dementia, and (2) identify determinants (barriers and facilitators) of implementation.

Method: PubMed, CINAHL, PsycINFO, Cochrane Library and Web of Science were searched for articles meeting the following criteria: The papers involved (1) an E-health (2) intervention for (3) informal caregivers of people with dementia and (4) provided information on the implementation of the intervention. The E-health interventions were online treatments, designed to improve health via the internet. Articles published before 2007 were excluded, as were non-English-language articles. Abstracts and full-texts were independently double screened and inductively analyzed using qualitative analysis.

Result: 47 articles containing 204 statements on implementation were included. Only one article mentioned 'implementation' in the title and four more studies were designed specifically as retrospective evaluations of barriers and facilitators to the development and implementation of E-health interventions. However, pilot studies, usability and feasibility studies, and trials also contained useful information on implementation. The 204 statements were grouped into four categories: Determinants associated with the (1) E-health intervention, (2) informal caregiver, (3) implementing organization or (4) wider context.

Conclusion: Despite prolific effectiveness and efficacy research on E-health interventions for caregivers of people with dementia, there is a critical dearth of implementation research. So far, the available findings have focused on characteristics of the intervention and the informal caregiver, with limited emphasis on essential factors such as organizational determinants and interaction with the wider context. This review also underscores the importance of future implementation research in bridging the gap between research and practice, and making these promising interventions available to the caregivers that need them.



PARALLEL SESSION ABSTRACTS

Environment and technology

Date: Sunday, 29 July 2018

25-005

MAPPING PROFILES OF PERCEIVED PARTICIPATION AND EVERYDAY TECHNOLOGY USE, AMONG PEOPLE WITH AND WITHOUT DEMENTIA IN SWEDEN

Sophie N Gaber*; Camilla Malinowsky and Louise Nygard, Division of Occupational Therapy, Karolinska Institutet, Stockholm, Sweden

Abstract:

Objective: Dementia is a world health priority. Globally, approximately 50 million people live with dementia and in the context of Sweden alone the figure of 150,000 people with dementia is predicted to double by 2050. The majority of people with dementia live in the community with ever-increasing opportunities to participate in activities both at home and within public space. However expanding opportunities to participate in society require engagement with an increasingly complex technological environment. Sweden has among the highest rates of technology use among over 65 year olds and this sample sheds new insight into the potential of technology to be both an aid but also a barrier to participation. This motivates the aim of the study to explore how profiles of perceived participation within public space relate to the amount of relevant technologies in the environment of people living with and without dementia.

Method: People living with mild-stage dementia (n=35) and people with no known cognitive impairment (n=34) in Sweden were interviewed using structured questionnaires, to explore the relevance of a range of Everyday Technologies e.g. kettle, mobile phone, self-service check-out, ticket machine, and to map perceived participation within public space.

Result: Based on the Swedish sample, people with and without dementia participate in a range of places within public space and there is a positive but small relationship between the perceived participation in the total number of places and the total number of technologies, perceived as relevant, among both groups.

Conclusion: The findings challenge the assumption that the physical and virtual world of the person with dementia shrinks. This indicates that a number of places and technologies both at home and within public space may benefit from being adapted to facilitate a more accessible and dementia friendly society.





PARALLEL SESSION ABSTRACTS

Carer support and training

Date: Sunday, 29 July 2018

26-001

SAFETY NET – A MENTORSHIP PROGRAM FOR CARERS

Meghan Williams*, Alzheimer Groupe (AGI), Montreal, QC, Canada

Abstract:

Alzheimer Groupe (AGI), a Montreal-based charitable organization, has developed a unique mentorship program called Safety Net, which helps family carers support a person living with dementia.

AGI-trained mentors guide carers through the healthcare system, provide information on how to access community services and plan for the future. Safety Net focuses solely on the family carer and has shown great benefit in reducing caregiver stress and their sense of isolation.

Design: Volunteer mentors receive training about their role and responsibilities, dementia and resources available. Mentors are former carers who have firsthand experience in the caregiving role. Once a mentor and mentee are matched, they decide the frequency of contact and the method by which they will communicate (e.g. face-to-face, email, phone). AGI's Program Coordinator follows up regularly with both the mentor and mentee to ensure that their needs are being met. Mentors have access to AGI's Counselors for any guidance they need.

Outcome: Safety Net was designed as a 2-year pilot project with continuation possible through clear outcomes. An evaluation with the mentors and mentees was completed at the end of each year. Throughout the pilot period, 18 mentees were paired; with a few mentors having more than one mentee. Evaluation results showed that 90% of mentees felt that Safety Net met their expectations. Benefits reported by mentees included: feeling supported, listened to and that the mentor referred them to appropriate resources. Overall, mentors felt 80% satisfied with their experience in the program. Mentors reported a high level of satisfaction in the realization that their experiences now benefit others travelling a similar road.

Next Phase: Following a successful pilot project, AGI continues to provide meaningful matches to benefit the carer. With the success of this first stage, Safety Net's next objective is to recruit mentors from various demographic backgrounds (including more male mentors and adult children). Moving forward, the Safety Net program will expand to focus more on the mentee's family and friends, thus creating a complete circle of support for the carer.





PARALLEL SESSION ABSTRACTS

Carer support and training

Date: Sunday, 29 July 2018

26-002

THE PRESTIGE PASSPORT FOR SUCCESS: AN EXPERIENTIAL STAFF TRAINING PROGRAM

Mrs. Julie K. Genthe*, Prestige Senior Living, Vancouver, WA; Hollie Fowler, Prestige Senior Living, Vancouver, WA and Mr. David Troxel, Best Friends Approach, Sacramento, CA

Abstract:

A 2015 study funded by the Alzheimer's Association noted that the US has a patchwork of training regulations related to staff working in residential dementia care. The report suggested training is inadequate in many states concluding that, "Many [staff] receive little or no training in the special needs of individuals with dementia, leading to avoidable situations in which people with dementia do not receive the care and treatment that is best for them." [Training to Serve People with Dementia: Is our Health Care System Ready? Paper 1: Issue Overview ISSUE BRIEF • AUGUST 2015. Burke & Orlowski].

Prestige Senior Living in Vancouver, WA operates memory care residential programs in the Western States and offers a memory care program called, Expressions. Aware of the challenges staff members face, Prestige rolled out a new program to enhance staff training and to make the experience more impactful, interesting, and fun.

The program is called the Passport program and its modeled on comparable products one might see at a trade show, where participants visit various booths, have their passports stamped by vendors, and then enter the passport into a raffle for prizes.

After initial training in dementia care, staff receive a Passport which invites them to engage in some follow up, experiential learning. Staff:

- Meet with a family care partner for an hour to discuss his or her experiences.
- Meet with department heads who support memory care to better understand their role, e.g. nurses and the building chef.
- Write a Life Story on a resident with dementia.
- Design and lead an activity in the memory care program.
- Participate in a care plan
- Enjoy a scavenger hunt looking for key programming supplies
- Tour the community to personally review safety features such as delayed egress systems on gates.

As they complete their tasks, their supervisor "stamps" that page of the Passport. When it's completed, the staff member receives recognition based upon their "graduation" from training that includes a polo shirt, certificate of commendation and other perks.

Results: To date, over 100 caregivers have finished the Passport training program and staff responses have been enthusiastic. Staff appreciate the opportunity to move beyond the classroom and apply their ideas in creative ways. Staff also view graduation from the Passport program as a milestone in their career development. The Passport program has also contributed to sustainability of the company efforts to build and maintain an excellent program where staff help create a therapeutic environment rich in friendship and activity. While evaluation is still underway initial findings support the idea that staff are approaching residents with more confidence and skill.



PARALLEL SESSION ABSTRACTS

Carer support and training

Date: Sunday, 29 July 2018

26-003

GOING BACK TO SCHOOL – PROVIDING LIFELONG LEARNING FOR PEOPLE WITH ALZHEIMER’S DISEASE IN DENMARK

Helle Kousgaard Hansen sr¹; Diana Schack Thoft sr²; Kim Michael Alberg Sørensen sr¹ and Alison Ward Sr³, (1)Voksenskolen for Undervisning og Kommunikation, Nørresundby, Denmark, (2)Department of Nursing, University College of Northern Denmark, Aalborg Øst, Denmark, (3)University of Northampton, Northampton, United Kingdom

Abstract:

Objective: The provision of lifelong learning for older people is often promoted as a way of engaging socially and maintaining cognitive function. Lifelong learning can also be relevant to people with dementia in relation to cognitive improvement and socially engagement, but often the learning opportunities is limited to short-term programmes. Innovative practice from the school of teaching and communication (VUK) in Denmark takes this concept further, offering people with early stage dementia the opportunity to return to school to attend classes in cognitive training, music, art and woodcraft etc..

The aim of this pilot study was to investigate whether people with early-stage dementia who attend VUK are able to obtain new knowledge, improve on, learn new skills and maintain this knowledge and these skills for a period of time (minimum twelve weeks).

Method: The study engaged twelve students with Alzheimer’s disease, with an average age 72 with a MMSE score of 14-29 (average score 21). Seven different cognitive activities were completed and tested for a period of 12-14 weeks. The activities ran over a 15-month period with regular testing on each activity being undertaken.

The tests measured visual memory, auditory memory, tactile recognition, short-term memory, working memory, vocabulary mobilisation and the ability of transforming elements to a whole.

Result: The activity method was based on the use of repetition, and testing showed improvements in the students’ performance across all seven aptitudes, with a variation of the number of students improving in each test from 43-100%. For example did 100% of the students show improvement in the test of visual memory, while 86% of the student showed improvement in the test of tactile memory.

Conclusion: The results offers evidence for the benefits of prolonged educational programmes for people with dementia in maintaining decision-making, cognitive function and social interactions, with limited evidence of the impact on memory. Further evidence is required to understand the impact of a person with dementia attending school as a student and to understand if this concept is transferrable to a different cultural setting.

The intention now is for a UK team, supported by the staff from VUK, to develop, implement, and evaluate a similar adult education model in the UK, which has been informed by the Danish concept. Given the significance of lifelong learning in Denmark, the aim would be to explore if the model is transferrable within an alternative cultural context. In addition, further evidential work is required to understand the potential impact of the VUK model on supporting retained mental capacity and personal capabilities for people in the early stages of dementia, and if intensive cognitive training delivered by teachers in an educational environment can slow cognitive decline, while enhancing self-confidence and esteem.

Student tests

Test	Activity	No. weeks to complete	No. student participants	Results
Visual memory	Recall of 10 objects (timed)	12	9 completed 1 non-complete	100% recalled more objects
Short-term memory	Repeat of a series of digits (up to 8 number series)	12	7 completed	57% improved on the number of digits repeated 29% remained the same 14% recalled fewer digits
Working memory	Repeat of a series of digits in reverse (up to 7 number series)	12	7 completed	43% improved on the number of digits repeated 20% remained the same 36% recalled fewer digits
Tactile recognition	Identification of 15 objects in a bag (timed)	12	7 completed	86% identified more objects 14% identified fewer objects
Word creation	Creating additional words from a long word (timed)	12	9 completed	78% created more words 12% remained the same 10% created fewer words
Recognition of auditory stimuli	Identification of 15 everyday sounds	12	8 completed 1 non-complete	100% identified more sounds
Transference of a learned skill	Completion of two puzzles (timed) – Puzzle A for weeks 1 and 14; Puzzle B, weeks 2-13.	14	12 completed 1 non-complete	70% improved their time to complete the puzzle 33% took longer to complete this puzzle



PARALLEL SESSION ABSTRACTS

Carer support and training

Date: Sunday, 29 July 2018

26-004

CRISP - CARERS' INFORMATION AND SUPPORT PROGRAMME: SUPPORTING AND ENABLING CARERS TO LEAD INDEPENDENT LIVES

Zoe Campbell Ms, Commercial Intelligence and Outreach, Alzheimer's Society, London, United Kingdom and
Jeremy Hughes CBE, Alzheimer's Society, London, United Kingdom

Abstract:

The Carers Information and Support Programme (CrISP) was developed following a review of current research findings and a series of focus groups for carers and Alzheimer's Society staff in 2010.

The design of CrISP was informed by Alzheimer's Society internal report (2010): *'Information needs of people with dementia and carers'*. This indicated that family carers wanted access to information as soon as possible after diagnosis and preferred printed information and guidance delivered face to face in an environment with peer support.

CrISP is delivered throughout England, Northern Ireland and Wales. It aims to improve the knowledge, skills and understanding of people caring for a person with dementia. The programme consists of two separate parts: CrISP 1 and CrISP 2. Each programme is delivered to small groups of up to 12 people.

CrISP 1 has been designed specifically for carers, family members and friends of people with a recent diagnosis of a dementia. It consists of four essential sessions:

- Understanding dementia
- Legal and money matters
- Providing support and care
- Coping day-to-day
- Next steps.

CrISP 2 has been designed specifically for people who have been living with dementia for some time. It consists of three essential sessions:

- Understanding how dementia progresses
- Living with change as dementia progresses
- Living well as dementia progresses, including occupation and activities.

Each CrISP course aims to:

- Increase knowledge of dementia.
- Improve access help and services
- Improve coping ability
- Help planning for the future
- Provide peer support and sharing

CrISP has been evaluated by Brighton University. The evaluation showed that carers valued the information and increased knowledge they received and the way that information was imparted in a supportive peer group environment where it could be explored with others.

Carers felt it enabled them to develop skills and confidence in supporting the person they cared for.



PARALLEL SESSION ABSTRACTS

- Experiential knowledge was valued highly by carers.
- The timing of information was critical
- The courses led carers to be more confident
- There was a less obvious impact on carers' capacities to secure support for themselves.
- The evidence from the evaluation and the experience and learning the Alzheimer's Society has gained through delivery of CrISP courses over the last 3 years, would be of benefit to other countries interested in establishing their own carer support programmes.
- We are willing to discuss our learning and how to establish CrISP approaches with interested parties.





PARALLEL SESSION ABSTRACTS

Carer support and training

Date: Sunday, 29 July 2018

26-005

BUILDING DEMENTIA CAPABLE COMMUNITIES TO SUPPORT PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS: A COMMUNITY-BASED AND INTERDISCIPLINARY APPROACH

Mr. Ryan Lavalley^{*1,2}; Jenny Womack^{1,2}; Marie Dagger²; Kim Lamon-Loperfido²; Lisa Meinert² and Mary Fraser²,
(1)Occupational Science and Occupational Therapy, University of North Carolina - Chapel Hill, Chapel Hill, NC,
(2)Aging, Orange County Department on Aging, Chapel Hill, NC

Abstract:

This presentation will describe the experience and lessons learned of occupational therapists, social workers, and activity coordinators collaborating on a 3-year-long community-based project funded by the Administration for Community Living called OC CARES (Orange County Caregiver Awareness Respite Education & Support). This project began in 2015 and was developed to enhance awareness of dementia, create and expand services for carers of people with dementia, and build a dementia capable community through the outreach of a county Department on Aging in North Carolina. Participants will learn about the benefits and challenges of a community-based and interdisciplinary approach to developing dementia capability of a community, exemplified in the OC CARES program.

This project was developed through a social ecological lens, and therefore strives to ameliorate any negative impacts of being a carer for someone with dementia from multiple social and ecological dimensions of the community. This approach includes support and training for carers including ongoing in-home coaching, respite programs, and support groups. Memory cafés also acted as an integral method of engaging people living with dementia and their carers together in the community. The project targeted the local work force by offering dementia education to direct care workers, public transit employees, county departments, and others. In order to develop dementia capability at the community level, a dementia-friendly business campaign has successfully trained over 75 local businesses, including banks, lawyers, pharmacies, markets, and more. Additionally, Dementia Education classes have been made free and publicly available that cover a range of topics including basics of dementia, communication strategies, providing activity, and environments and technology.

These various services offered through OC CARES were provided by a collaborative and interdisciplinary team based in a county Department on Aging. This team will present the lessons they have learned as they continue to work together through all dimensions of the community to support the rights, well-being, and quality of life of people with dementia and their carers. The interdisciplinary nature of the project serves to inform the team's approach to complex and multi-layered care situations. This strength especially emerged in reaching out to and serving people with dementia who are living alone. The collaboration and continued conversation among team members is integral to the wrap-around network of community-based services provided by the Department on Aging.

Participants of the presentation will develop awareness of the international dementia- capable and dementia-friendly movements, explore the different roles of healthcare and community entities in providing collaborative and interdisciplinary support for people with dementia and their carers, and will be encouraged to explore how this model of support for carers might be beneficial in their local area. They will gain insight into the advantages and challenges of situating dementia support services in community-based organizations and tailoring support services to the needs and social situation of each care cohort. This will improve the participants' knowledge of comprehensive approaches to supporting continued engagement and quality of life for people living with dementia and their carers in the community.



PARALLEL SESSION ABSTRACTS

Carer support and training

Date: Sunday, 29 July 2018

26-006

HOLISTIC CAREGIVER SUPPORTING GROUPS

Dr. Chien-Liang Liu^{*1}; Pei-Jhen Lin² and Ya-Chuan Hsu¹, (1)Dementia Center, Taipei City Hospital, Taipei, Taiwan, (2)Taipei City Hospital, Taipei, Taiwan

Abstract:

Objectives: Living with a person with a diagnosis of dementia is life changing. The carer would encounter different challenges in the care period. Supporting a person who had dementia needs the knowledge of care skills, resource management and emotional or spiritual wellbeing. We also consider how to facilitate these caregivers participate and generate new care resources from these supporting groups.

Since 2014, we have developed 12 topics for care skill training and we held this activity on a weekly basis. This group is cyclic and is capable of dynamically modifying the topics to cover the care needs in the whole disease course, from mild cognitive impairment to terminal dementia, even to hospice care needs. The topics had been extended from 12 to 24 topics now. We used the social media (LINE) to generate the group and distribute the information of care.

From year 2017, we added the support groups for emotional and resource management, which had been hold by psychologist and social worker. We transferred caregivers to different supporting groups according to their needs which came from the assessment by doctors, care managers or group facilitators. Moreover, we provided life event party such as birthday party, caregiver meeting and yearly traveling with their family members with dementia to facilitate the intragroup and intergroup connection.

We provided the group size of skill training around 20-30 caregivers, emotional supporting in 8-10 caregivers, and resource management in 2-4 caregivers. The skill of care can be significant improved after weekly training course for 4 months. For the high stress, depressed and anxious caregiver, the staff recommended the carer to participate in emotional supporting groups. If we found some family issue or problem of resource management, we would refer to resource management group and help the caregiver to reorganize the resources and provided information of external and informal resources.

Conclusion: We provided a holistic caregiver groups for skill training, emotional support and resource management. In conclusion, this model of care is good for managing the complex needs of a carer, family member or friend of a person with dementia.





PARALLEL SESSION ABSTRACTS

Younger onset dementia

Date: Sunday, 29 July 2018

27-001

UNDERSTANDING THE UNIQUE NEEDS OF SUPPORTING PEOPLE AND THEIR FAMILY MEMBERS WHO ARE LIVING WITH YOUNGER ONSET ALZHEIMER'S DISEASE: A REVIEW OF LESSONS LEARNED FROM THE FOURTEEN YEARS OF THE RUSH ALZHEIMER'S DISEASE CENTER'S WITHOUT WARNING PROGRAM

Susan M Frick*, Rush Alzheimer's Disease Center, Chicago, IL

Abstract:

Since 2004, the Rush Alzheimer's Disease Center (RADCC) has offered a support program for people living with younger onset Alzheimer's disease (AD) called Without Warning (WW). Over its 14-year history, this program has become the largest of its kind in the country, offering ongoing, free support to the entire family living with AD in mid-life.

WW's monthly meetings offer groups for the person experiencing AD, their family members, friends and at times paid caregivers. The group currently averages 60 people per meeting. At the general meeting, two groups are offered for people with AD, a verbal and a music therapy group, and up to four groups for family members— an early, middle, late stage groups and a bereavement group. A group for adult children meets bi-monthly and a group for young children meet when needed.

The WW program is currently creating a framework for replicating a younger onset support program. This framework includes:

1. Keeping the voice of the people living the experience center to the process

Two WW Advisory Councils meet regularly giving guidance and direction to the program, with one made up of people with AD and the other of family members. Both councils give guidance to the group meetings, special projects, and social events. Also, focus groups were offered to gather opinions on the WW program and regular surveys are utilized with all members to assess the program.

2. Sharing the Story

WW members learn to share their stories, initially in the group sessions and then to the greater community, which include health care professionals, clergy, students and the public. Group members have been involved in interviews, film projects and panel presentations, which share life with AD, how this experience changes them, and how community can be a support. In the group's 14-year history, members have presented to thousands of people. To further the reach of the WW program, nine families were filmed for the just released documentary, *Too Soon to Forget: The Journey of Younger Onset Alzheimer's Disease*. This documentary looks at the emotional experience of the illness and the important role of community support.

3. Providing a Continuum of Resources to Match the Changes of the Experience

To better understand the unique needs of people with younger onset AD, over 200 groups sessions were recorded and many transcribed. Quality analysis was utilized to look at common themes discussed. Understanding the common issues of people living with younger onset AD is vital for group facilitators.

4. Create a Space Where Families Share Without Judgment



PARALLEL SESSION ABSTRACTS

5. Offer Social Activities

Younger onset AD is a lonely and isolating experience. To help reduce this feeling, WW offers social time at each meeting along with regular social events.

The RADC's WW program has a long successful history which can be utilized by others to develop programs for this underserved group of people living with AD at a young age.



PARALLEL SESSION ABSTRACTS

Younger onset dementia

Date: Sunday, 29 July 2018

27-002

LONGITUDINAL COGNITIVE ASSESSMENT IN SUBJECTS WITH DOWN SYNDROME WITH AND WITHOUT COGNITIVE DECLINE

Juan Fortea Dr¹; Laura Videla Toro Nps²; Bessy Benajam Paul Nps²; Susana Fernández González Dr²; Maria Carmona Iragui Dr³; Jordi Peguerols Monllau¹; Isabel Barroeta Espar¹; Sebastián Videla Ces⁴; Alberto Lleó Bisa Dr¹ and Rafael Blesa González¹, (1)Neurology, Hospital de la Santa Creu i Sant Pau, Barcelona, Spain, (2)Neurology, Fundació Catalana Síndrome de Down, Barcelona, Spain, (3)Neurologu, Hospital de la Santa Creu i Sant Pau, Barcelona, Spain, (4)Farmacology, Hospital de Bellvitge, Barcelona, Spain

Abstract:

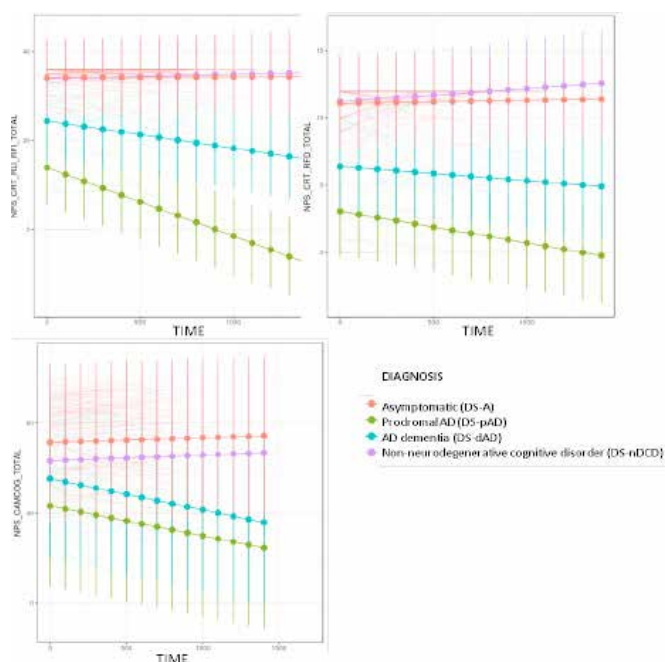
Objective: Down syndrome (DS) is a genetically determined form of Alzheimer disease (AD).

However, AD diagnosis represents a diagnostic challenge in this population due to the intellectual disability associated with DS. The main objective of this work is to describe the cognitive trajectories of a cohort of people with DS.

Method: Adults with Down syndrome participating in the prospective longitudinal project Down Alzheimer Barcelona Neuroimaging Initiative (DABNI) with at least one year follow-up were included. Participants were classified as asymptomatic (DS-A), prodromal AD (DS-pAD), AD dementia (DS-dAD) and non-neurodegenerative cognitive disorder (DS-nDCD) after a comprehensive neurological and neuropsychological evaluation, which included the CAMCOG-DS and the Cued Recall Test (CRT). We analyzed the progression to prodromal AD and the conversion to AD dementia. We also analyzed the longitudinal trajectories of the CAMCOG-DS and the Cued Recall Test (CRT) by diagnostic category through linear mixed effects (LME) models.

Result: From June 2014 to January 2018, 325 subjects were evaluated. 31 (9,5%) had dAD and 34 (10,5%) had pAD. The prevalence of dAD and pAD increased exponentially with age. The mean follow-up was 15 months (range 3 to 43). At one year follow-up there was a change of diagnostic group in 7% of the DS-A (to DS-pAD) and in 19.7% of the DS-pAD (to DS-dAD). The CAMCOG-DS and the CRT trajectories significantly differed by diagnostic category (figure 1)

Conclusion: Down syndrome (DS) is at ultra-high risk for Alzheimer disease. Population based screening programs assessments with longitudinal follow-ups performed by specialized personnel are needed for early detection and management of AD in this population.





PARALLEL SESSION ABSTRACTS

Younger onset dementia

Date: Sunday, 29 July 2018

27-003

YOUNGER ONSET DEMENTIA: THE IMPACT ON RELATIONSHIPS, INTIMACY AND SEXUALITY IN MIDLIFE COUPLES

Kristen Yvonne Holdsworth Ms^{*}, Psychology, Swinburne University, Melbourne, Australia

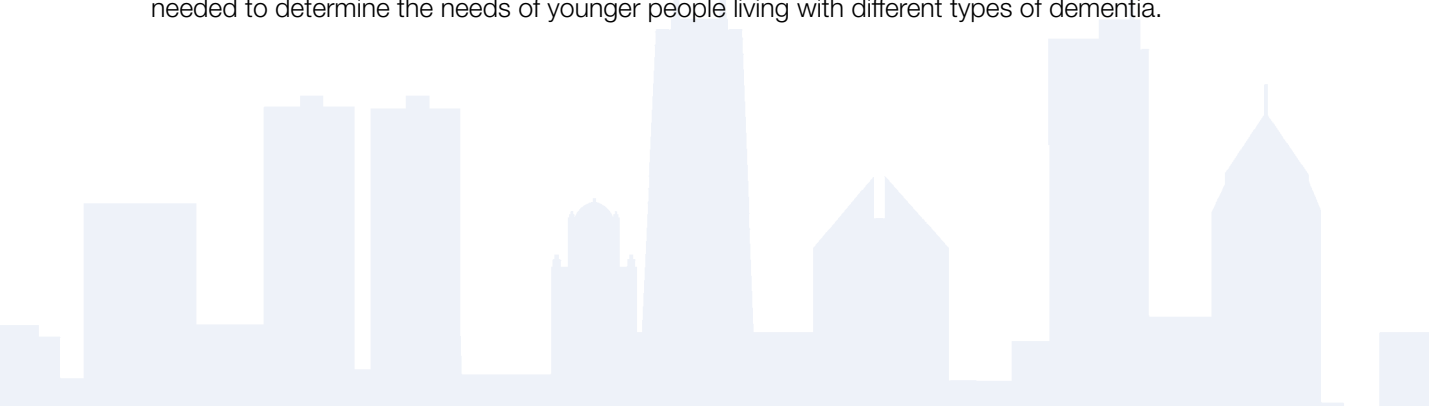
Abstract:

Objective: The onset of dementia often has a significant impact on the couple relationship. Research conducted with couples living with later onset dementia suggests changes in several key areas of the relationship; however, little is known about the experiences of couples living with younger onset dementia. The purpose of this phenomenological study was to explore the impact of younger onset dementia on relationships, intimacy and sexuality from the perspective of the partner, the person with dementia and the couple jointly. The study also investigated the education and information needs of service providers working with individuals and couples living with younger onset dementia regarding relationships, intimacy and sexuality.

Method: Purposive sampling was used to recruit people with younger onset dementia, partners and service providers. Participants were interviewed individually and couples jointly using semi-structured open-ended questions. A total of 24 interviews were conducted. Participants were 5 people with younger onset dementia, 8 partners, 5 couples and 6 service providers. Interviews were audio-recorded, transcribed verbatim and reviewed to develop a coding scheme. One researcher conducted a line-by-line review of the transcripts to identify themes and sub-themes. These themes were then reviewed and validated by a second researcher throughout the coding process.

Result: Analyses of the data identified four key areas: (1) qualities of the partner relationship, (2) level of intimacy in the relationship, (3) sexual activity and satisfaction, and (4) information, programs and supports. Participants with younger onset dementia and partners reported considerable changes in the relationship due to younger onset dementia; despite these changes, individuals and couples worked towards maintaining closeness in the relationship. Nearly all participants discussed the need for the development of specific resources regarding younger onset dementia and intimacy and sexuality, and greater opportunities to discuss relationship changes in peer groups, one-on-one counselling sessions, and with service providers. Many service providers described the need for additional staff education and training to better enable them to have open discussions with clients with younger onset dementia and partners regarding potential changes in relationships, intimacy and sexuality.

Conclusion: The results of the study have important implications including the need to develop younger onset dementia-specific resources regarding relationships, intimacy and sexuality. These resources should be produced with consumers to ensure the efficacy of the information provided, and the mode of delivery of information is appropriate. The development of training and education for service providers regarding the needs of people with younger onset dementia and partners in relation to relationships, intimacy and sexuality is essential to facilitate open communication between service providers and consumers. Additional research is needed to determine the needs of younger people living with different types of dementia.





PARALLEL SESSION ABSTRACTS

Younger onset dementia

Date: Sunday, 29 July 2018

27-004

RHAPSODY – SUPPORT FOR FAMILY CAREGIVERS OF PEOPLE WITH YOUNG ONSET DEMENTIA

Ms. Sabine Jansen^{*}, Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe
Demenz, Berlin, Germany

Abstract:

Informal carers of people with young onset dementia (YOD) may be more burdened than carers of older-age individuals with dementia due to existing work and family responsibilities. They have children to support and may face financial difficulties when the person with dementia cannot work. The prevalence of YOD is low and the medical and social support system is not appropriate for families coping with YOD.

An international consortium of six universities, one patient organization and one multimedia technology company from six European countries worked together between 2014 and 2017 to develop an internet-based resource for caregivers of people with YOD. In seven chapters, the program (called Rhapsody) provides information and support relevant to YOD. A pilot study was conducted in France, England and Germany to determine the feasibility of delivering the program, its likely acceptance and potential impact. The intervention was positively evaluated by the participants and the platform is now available to the public in Germany, France and Portugal.





PARALLEL SESSION ABSTRACTS

Younger onset dementia

Date: Sunday, 29 July 2018

27-005

UNDERSTANDING THE NEEDS OF PEOPLE WITH YOUNG ONSET DEMENTIA: PROCESS, PRODUCTS AND PARTNERSHIPS

Mary Schulz, Information, Support Services and Education, Alzheimer Society of Canada, Toronto, ON, Canada and **Laura Garcia**^{*}, Education, Alzheimer Society of Canada, Toronto, Canada

Abstract:

Young onset dementia (YOD) is defined as dementia diagnosed before the age of 65. YOD accounts for 2-8% of all dementia cases (World Alzheimer Report, 2015). Individuals with YOD face many unique difficulties starting with obtaining an accurate diagnosis, which can cause considerable stress for the individual and their families (Baptista, 2016). In addition, the personal and social consequences of YOD differ from those experienced by individuals diagnosed with dementia later in life.

A lack of knowledge about YOD exists among health and social care providers (HCP) which adds to the difficulties and lack of available support.

The Alzheimer of Canada (ASC) conducted two projects to get a better understanding of the YOD experience in order to address the gaps in current knowledge and to improve the experience of living with YOD.

ASC conducted a gap analysis regarding available learning and support resources for individuals with YOD. As part of the analysis, advice and feedback was gathered from those with lived experience. ASC also engaged persons with YOD to plan and deliver a webinar for HCP about living with YOD. The goals of the webinar were to raise awareness of YOD and to provide strategies to help HCP support individuals with YOD.

The analysis revealed that there is a lack of available information to serve the needs of this population. Specifically there is a need to: 1) develop resources for youth who support persons with YOD; 2) create support groups specifically for YOD; and 3) investigate web based learning and support resources for persons with YOD, their caregivers and their children. In addition, as a result of persons with YOD planning and delivering the webinar, ASC gained valuable lessons on shared leadership and project logistics.

Results from these projects will inform the development of resources for both HCP supporting individuals with YOD, and for people with YOD and their caregivers. In addition, lessons learned from involving people with YOD will inform the process that ASC follows in engaging people with YOD throughout the organization.





PARALLEL SESSION ABSTRACTS

Younger onset dementia

Date: Sunday, 29 July 2018

27-006

ROLE AND IDENTITY: YOUNGER ONSET AND CARING

Pamela Sogge*, Delinia Consulting, Oakland, CA

Abstract:

Younger onset Alzheimer's disease presents unique challenges for the early middle-age caregiver. Onset occurs at an age that many are in or reaching the height of their professional careers. A psychological toll paid when partners in their 50s shift their professional and home lives to care for their loved one with an Alzheimer's disease diagnosis.

The author details the phases of her caregiving, and the approaches that have helped in each phase.

1. Initial Diagnosis:

- Focus on health. 150 minutes of high heart rate. Hand eye climbing. Nutritional, legal, financial, medical health.
- Clinical trial participation
- An improvisational approach to life with Alzheimer's Disease

2. Goal orientation, making most of remaining life together

3. Depression and Decline. Self identify in caregiving while wage earning.

5. Move to in home care.

The talk is not scientific, but practical, personal, specific, both serious and lightly humorous.

The struggle of the last four years has been largely mine – at first, “what should I do?” more recently, “who am I?” and throughout, “how can I ask for help?”

With the initial diagnosis, I approached this role as I would a new profession; I had goals and tasks I faced with enthusiasm. My job was to make the most of everything, find enough work to pay our bills, create meaningful time together, and to help Rick be as mentally and physically as fit as possible. A few things helped measurably in this initial phase:

1) Focus on health. We hiked vigorously, Rick continued to Rock Climb with his friends. I worked on getting our legal and financial health in order, redid our finances, wills, and healthcare directives. I cooked awesome meals.

2) Clinical trial participation helped us move forward with our new reality. In that bubble of trial coordinators, phlebotomists, nurses, and doctors, we were treated with great dignity while openly being a couple living with Alzheimer's disease

3) An improvisational approach to life with Alzheimer's Disease

The concept of improv is that you make it up as you go along; a natural for living with Alzheimer's. The improve rules that worked for me are:

- Say “yes” to your partner
- Expand on that “yes”: known as “yes, and”
- And always make your partner look good.



PARALLEL SESSION ABSTRACTS

Say “yes” to your partner

You can learn to say “yes”. Imagine you are running errands, and have decided to eat. You ask your partner, “should we go to the deli, or the taco shop?” He replies, “the art store is right there.”

Normally, I’d say, “we are going out to lunch, they don’t have food at the art store.” Instead, I say “yes” to his line of thought: “You’re right, Blick is right there.”

Pause a minute, and think about Rick’s experience in these two short situations. Dramatically different.

Yes, and...

Rule 1 is to say “yes”, not “yes, that’s nice dear” but yes.

With Rule 2, you add something to that “yes”. Yes, there’s the art store, and do you want to go in? Yes, the plant is blooming, and let’s go look at it. Adding onto your partner’s “yes” affirms what they’ve said, while opening a world of new possibilities. Suddenly, the art store isn’t wrong, it’s a new and beautiful addition to your day.

Building onto the “yes” is particularly important in social situations, which leads me to the third rule...

Make your partner look good

Sometimes I feel the pull of the, “see what I have to put up with” eye-roll. We naturally want to distance ourselves from illogical, socially odd behavior; to show we are not that way. *The Make Your Partner Look Good rule* reminds us to fight the eye-rolling impulse, and support our partner.

YOUNGER ONSET SPOUSE

Living Life with Alzheimer’s Disease in the House





PARALLEL SESSION ABSTRACTS

Rights of people with dementia

Date: Friday, 27 July 2018

4-001

IS NOT BEING TOLD A DIAGNOSIS OF DEMENTIA A VIOLATION OF A HUMAN RIGHT? A SYSTEMATIC REVIEW OF PRACTITIONERS' PRACTICES AND ATTITUDES

Lee-Fay Low^{*}, University of Sydney, Sydney, Australia; Kate Swaffer, Dementia Alliance International, Adelaide, Australia; Margaret McGrath, University of Sydney, Lidcombe, Australia and Henry Brodaty, Centre for Healthy Brain Ageing (CHeBA) and Dementia Centre for Research Collaboration (DCRC), School of Psychiatry, Medicine, UNSW Sydney, Sydney, Australia

Abstract:

Objective: The aim of this study is to systematically review practitioners' practices and attitudes in regards to communicating a diagnosis of dementia.

Method: A systematic search was conducted of Scopus, Web of Science and PubMed for English language original empirical papers. Both quantitative and qualitative papers were included with a sequential explanatory mixed studies analysis approach used.

Result: From an initial pool of 7453 papers, 25 quantitative descriptive, two intervention, six mixed methods descriptive and 21 qualitative studies were included. Pooled analysis showed that 34% of GPs and 48% of specialists usually/routinely tell the person with dementia their diagnosis, and 89% of GPs and 97% specialists usually/routinely tell the family the diagnosis. Euphemistic terms such as 'memory problems' are more often used to describe dementia than medical terms. Practitioners' decision to diagnose and communicate the diagnosis of dementia are influenced by a) their own beliefs regarding dementia and treatment efficacy, and their confidence in diagnosis and communication; b) patient circumstances including level of awareness, level of severity and family support; c) the health and social care system including access to specialist and diagnostic services, reimbursement for diagnosis/management and availability of services; and d) cultural norms in relation to dementia including stigma, labels, and common clinical practice.

Conclusion: It is a violation of human rights of persons with dementia that they are not told their diagnosis by more than half of health practitioners. Multicomponent approaches to address these practices could include a) guidelines on how to communicate the diagnosis developed with the involvement of practitioners, people with dementia and their care partners; b) practitioner training on the intertwined processes on diagnosis and communicating the diagnosis; c) anti-stigma public health campaigns which will reduce fear and misconceptions make it more acceptable for people with dementia to seek assessment and reduce the negative connotations when the diagnosis is communicated making this easier; d) offering post-diagnosis treatments and support which gives more reason for people with dementia and practitioners to talk about the diagnosis, and e) sufficient reimbursement for practitioners for time spent managing dementia so that they have enough time to spent talking to patients.



PARALLEL SESSION ABSTRACTS

Rights of people with dementia

Date: Friday, 27 July 2018

4-002

RIGHTS OF PEOPLE WITH DEMENTIA IN PRISON: A SCOPING REVIEW

Joanne Mary Brooke Dr; **Alicia Diaz-Gil** and Debra Jackson Prof, OxIMNAHR, Oxford Brookes University, Oxford, United Kingdom

Abstract:

Objectives: The risk of dementia within the prison population maybe higher than that of the general population this may be due to accelerated aging, poor health and lifestyle choices, and higher rates of brain injuries and psychiatric morbidities of prisoners. The aim of this scoping review was to explore dementia within the prison setting. The specific objectives were to identify 1) the prevalence and incidence of dementia within the prison population 2) strategies to assess and diagnosis prisoners for dementia 3) strategies to support prisoners with dementia during their sentence and resettlement process and 4) strategies to support staff within custodial services.

Methods: A scoping review was undertaken to examine the extent, range and nature of research regarding dementia within the prison setting. The methodological framework for scoping reviews developed by Arksey and O'Malley (2003) was adhered to, which included 1) identifying the research questions, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarizing and reporting the results. Databases searched included: CINAHL, PubMed, BNI, PsychINFO, EMBASE and Medline, studies presenting primary data for prisoners with cognitive impairment or dementia in the prison setting, published from 1st January 2000 to 31st December 2017 in the English Language were included. Due to the diverse methodological approaches of studies a thematic analysis as described by Braun and Clarke (2006) was completed.

Results: The final number of papers included in this scoping review was 14, these were completed in a number of countries; USA (n=6), UK (n=4), Australia (n=2), France (n=1), and Sweden (n=1). The number of participants within the studies included; prisoners - 11-262 (n=1,237), nurses and healthcare professionals - 18-36 (n=83), correctional officers - 71, legal representatives and advocates - 72, and a comparison with community dwelling males - 138. Issues arising from the analysis included: prevalence, psychiatric referrals and diagnosis, identification of the needs of prisoners with dementia, interventions and services to support older prisoners, and knowledge of correctional officers and legal professionals.

Conclusion: Prevalence within prison settings ranged from 1 – 7%, of those over the age of 60 deemed to be legally insane dementia was identified and acknowledged as the cause in 12% of these prisoners. National experts in correctional health recognise dementia is not being diagnosed within the prison setting and recommended routine screening for dementia in prisoners from the age of 50, with screening tools specifically developed for this population. Interventions for older prisoners have been developed, although very few specifically supported prisoners with dementia. The knowledge of correctional staff, healthcare and legal professionals' ability to identify cognitive impairment in prisoners was limited. The Human Rights of prisoners with dementia are being neglected with insufficient screening, assessment, diagnosis and care and support during their prison sentence and on resettlement.

References:

Arksey, H., O'Malley, L. (2005). Scoping Studies: Towards a Methodological Framework. *International Journal of Social Research Methodology* 8(1): 19-32.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101.



PARALLEL SESSION ABSTRACTS

Rights of people with dementia

Date: Friday, 27 July 2018

4-003

A HUMAN RIGHTS BASED APPROACH TO DEMENTIA RESEARCH

Bernadette Rock Dr*, Research, Alzheimer Society of Ireland, Dublin, Ireland

Abstract:

"My journey shows that people with dementia are more than just a condition; they are citizens who want active lives and have fundamental needs", Helen Rochford-Brennan, European Working Group of People With Dementia.

Indeed, as Kitwood (1997) states, *"all persons have fundamental needs for love, inclusion, attachment, comfort, identity and occupation, which it could be argued, become more critical with dementia"*.

In April 2016, The Alzheimer Society of Ireland (ASI) and the Irish Dementia Working Group published a Charter of Rights for People with Dementia, calling for greater participation, accountability, equality, empowerment, and legal recognition for the rights of people with dementia. The Charter adopts the principles of PANEL, which refer to Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality.

Significantly, the ASI strives to encompass and impart these rights and principles in its research on people with dementia. The ASI carries out *research* into key areas that can influence and improve the quality of life of people with dementia and carers, and receives a high volume of research requests. The ASI's Research Review Committee approaches research and ethical issues using the human rights based approach of Panel. Panel provides a framework with important elements to keep in mind if we want to promote respect for the rights of people with dementia in research.

This presentation explores the process by which the ASI addresses ethical issues in research using a human rights Panel approach. It explains how approaching ethical issues through a human rights lens helps ensure that the rights of people with dementia are put at the very center of research and that those with dementia are empowered to be as involved as possible in research.





PARALLEL SESSION ABSTRACTS

Rights of people with dementia

Date: Friday, 27 July 2018

4-004

OUR RIGHTS, OUR VOICE: CO-PRODUCTION AT THE HEART OF THE NEW DEMENTIA STATEMENTS

Keith Oliver* and Hannah Fitzgibbon Ms, 3 Nations Dementia Working Group, Alzheimer's Society, London, United Kingdom

Abstract:

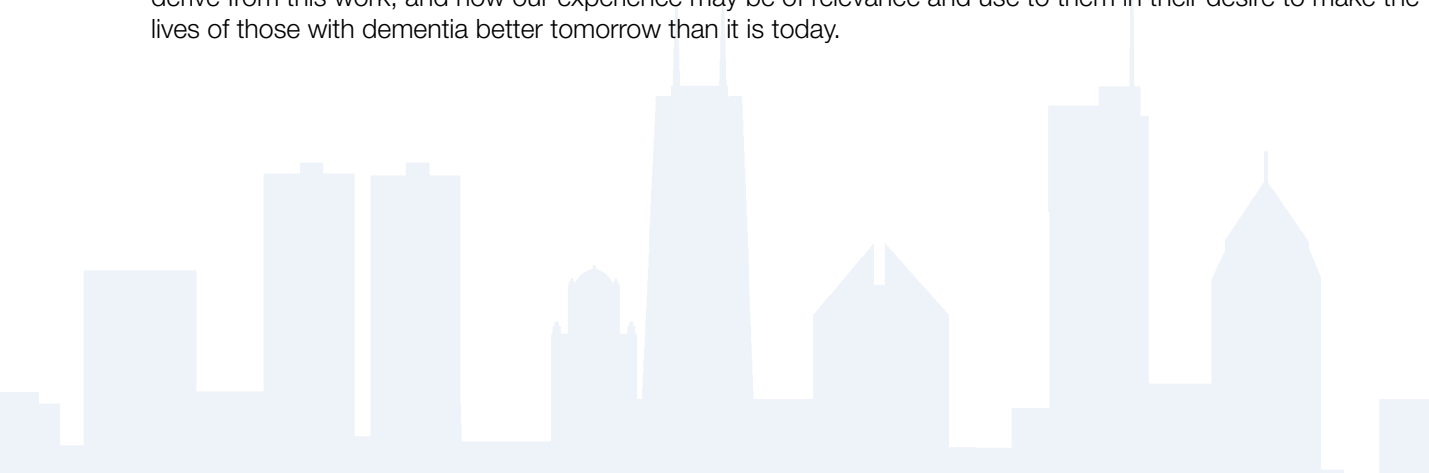
In 2010, 41 organisations which later went on to form the UK's national Dementia Action Alliance, asked people affected by dementia and other key organisations what type of care and support they would hope to receive in the future. Informed by these conversations, they created the National Dementia Declaration, a set of seven expectations or Statements of what life should be like for people with dementia. These statements were a central thread of policy and practice up until 2017, when they were reviewed and re-written with the rights of people affected by dementia at their core. The original Statements became known widely as the "I" statements, and the updated version replaces this with "We" in acknowledgement of the impact dementia has on both the person with the diagnosis and those closest to us. This is also important in how the statements were written and how we seek to implement them.

At the same time as the launch of the new 'Dementia Statements', the Three Nations Dementia Working Group was formed. This is a group of people with a diagnosis of dementia who are totally committed to driving forward change for people affected by dementia in England, Wales and Northern Ireland.

Our presentation will follow how and why these statements were reviewed and re-written, with professional support, by people affected by dementia at the helm steering, influencing, generating and evaluating the revision in order that the fundamental issue of rights is clear in each statement - an excellent example of coproduction in practice. We believe these statements are the authentic voice of those affected by Dementia.

We will explore the national significance of the statements in contributing to driving policy at all levels, and to greater involvement in this by people affected by dementia. We will also explore the Dementia Statements in an international context and how they were used by the author in his presentation to the UN Committee on the Convention on the Rights of Persons with Disabilities in Geneva in August 2017. To the best of our knowledge he was the first person with dementia to present to this committee.

Whether informing domestic policy or practice, or at an international level advocating for change at the UN, the new Dementia Statements provide us with an opportunity to now ensure that the rights of people with dementia are at the heart of everything we do. Our presentation, delivered by members of the Three Nations Dementia Working group, living with dementia, will seek to show the learning from our experience that other countries may derive from this work, and how our experience may be of relevance and use to them in their desire to make the lives of those with dementia better tomorrow than it is today.





PARALLEL SESSION ABSTRACTS

Rights of people with dementia

Date: Friday, 27 July 2018

4-005

PREJUDICE, INDEPENDENCE, RIGHTS: VIEWED FROM THE PERSPECTIVE OF THE PEOPLE WITH DEMENTIA

Mr. Tomofumi Tanno*, Orange Door; Working Group Miyagi, Sendai, Miyagi, Japan

Abstract:

To think about the “prejudice” of dementia.

After receiving my diagnosis, I recognised that I was just the same person before the diagnosis except for forgetfulness and getting tired easily.

Dementia is just a part of me, and most of the functions are almost the same so far.

However, people around me didn't think so. They thought that I would have become unable to do anything.

I think they were influenced by the media reports about dementia which always pay attention to severe dementia decline, and they had believed that I would become nothing to do gradually, then I would trouble them.

I think prejudice exist in my and my family's heart.

People with dementia tend to care about the perspective around them even if people with dementia have never experienced the pressure and the prejudice words from around them.

Next, about independence,

I think the meaning of “independence” is not to do everything by ourselves, is to do what we can do even if we get the support.

However, people around us deprive us of what we want to do. At the same time, they say that “This is a risk for you. Who is responsible for this?”

I would like you to know that people with dementia don't want to protect themselves unduly, but want to come together and encourage each other, by promoting their independence.

Finally, about the rights,

After my continuous thinking about the prejudice and independence of people with dementia, I recognised that people with dementia also have equal rights to be able to live ordinary lives and to do what we want to, the same as before.

People around us tend to prohibit our daily routines in the ordinary life because of the risk. We people with dementia are overwhelmed by them, we worry about being in the public eye, we become having a prejudice against ourselves.

I think prejudice, independence and rights are not the separate ones but connected straight.

If the prejudice remains, we cannot get independence and rights; we are regarded as the being weak and people around us protect us too much from risk.



PARALLEL SESSION ABSTRACTS

Diagnosis, treatment and research

Date: Friday, 27 July 2018

5-001

INDIVIDUAL RISK FACTORS FOR POSSIBLE UNDETECTED DEMENTIA AMONGST COMMUNITY-DWELLING OLDER PEOPLE IN NEW ZEALAND

Gary Cheung*, University of Auckland, Auckland, New Zealand

Abstract:

Objective: There is general acknowledgement of the importance of early diagnosis of dementia, yet there are still high rates of undetected dementia internationally. The aim of this cross-sectional study was to determine the sociodemographic characteristics associated with possible undetected dementia in a large sample of community-dwelling older New Zealanders.

Method: The sample consisted of older people (age \geq 65) who had received the homecare version of the international Residential Assessment (interRAI HC 9.1) over a 2-year period and who were screened positive for possible dementia on the interRAI's Cognitive Performance Scale (CPS). People with possible alternative explanations for impaired cognitive performance such as depression and other neurological conditions were excluded from analysis. The 5202 eligible individuals were categorized into two groups: (1) those with a recorded diagnosis of dementia (64%) and (2) those without a recorded diagnosis of dementia (i.e. possible undetected dementia group) (36%). Logistic regression was used to evaluate the association between individual characteristics and possible undetected dementia.

Result: Significant risk factors for being in the possible undetected dementia group included Asian ethnicity (OR=1.9, CI=1.-2.7), living alone (OR=2.0, CI=1.8-2.3), not having participated in long-standing social activities recently (OR=1.4, CI=1.2-1.6), major life stressors (OR=1.9, CI=1.7-2.1), and limited accessibility of their house (OR=1.4, CI=1.1-1.8).

Conclusion: The knowledge gained from this study could enable targeting of services and resources for the groups at risk of undetected dementia to have a more equitable access to early diagnosis.





PARALLEL SESSION ABSTRACTS

Diagnosis, treatment and research

Date: Friday, 27 July 2018

5-002

CAREGIVER PERSPECTIVES ON DEMENTIA CARE IN THE PRIMARY CARE SETTING: A QUALITATIVE STUDY OF STRENGTHS AND CHALLENGES

Dr. Alissa S Bernstein¹; Jennifer Merrilees²; Sarah Dulaney²; Winston Chiong²; Katherine L Possin² and Katherine P Rankin³, (1)Global Brain Health Institute, Institute for Health Policy Studies, San Francisco, CA, (2)Department of Neurology, UCSF Memory and Aging Center, San Francisco, CA, (3)Department of Neurology, University of California San Francisco, San Francisco, CA

Abstract:

Objective: In the United States, primary care providers (PCPs) are often the first to screen and evaluate people living with dementia, and are heavily involved in their care management. PCPs have identified systems-level barriers to the assessment, diagnosis, and management of dementia, including the lack of technological, financial, and human resources, as well as inadequate time and expertise to educate people living with dementia and their families after a diagnosis. While much work has focused on the perspectives of PCPs regarding their practices in dementia assessment and management, less is known about the experience of care from the perspective of family caregivers. In this study, we examined experiences in the primary care setting from the perspective of family caregivers of people living with dementia.

Method: The study population was comprised of fifteen primary caregivers (spouse, child, or friend) of people living with dementia. Data consisted of qualitative semi-structured interviews that included questions focused on experiences related to dementia assessment and care within the primary care setting. Responses were analyzed for themes using an iterative process of thematic coding by a multidisciplinary team. Initial themes were categorized as: focus of primary care provider; strengths of the primary care experience; and challenges faced during the primary care experience. We identified exemplary quotes within each theme.

Result: Caregivers reported that PCPs focused primarily on physical assessment (blood work, labs, blood pressure) and medications. In regards to strengths of primary care management of dementia, caregivers reported feeling they could talk to the PCP due to their existing ongoing relationship, the PCP affirming their decisions or choices, the PCP being readily available when needs arose, and the PCP expressing concern with the caregiver's health and wellbeing. Most caregivers expressed consistent views with regard to challenges experienced in the primary care setting. These included difficulty convincing the provider of the need for evaluation for cognitive concerns, attributing cognitive deficits to conditions other than dementia, focus on physical ailments not social assessments and concerns, the feeling of not being listened to or heard, not receiving dementia-specific education, and not spending time during medical appointments focused on dementia.

Conclusion: Caregivers of people living with dementia shared insights into aspects of the doctor-patient dynamic when addressing dementia in the primary care setting. Caregivers identified a clear need for better diagnostic protocols that could be initiated by family member concerns, as well as additional social supports and dementia-specific education. Programs that augment primary care, such as assessment tools or care coordination models, may address these deficits. Additional work is needed to identify mechanisms for practice improvements.

COMBINING MATHEMATICAL MODEL AND CATECHOLAMINES QUANTIFICATION TO SCREEN ALZHEIMER DISEASE FROM A SIMPLE BLOOD TEST

Abstract:

Objective: Cerebrospinal fluid (CSF) biomarkers of Alzheimer's disease (AD) and amyloid-PET reliably reflect brain neuropathological AD lesions leading to their inclusion into AD criteria. However, these biomarkers are costly and invasive and new simple biomarkers are needed. Several studies have established a link between morphological and functional changes occurring in the monoaminergic ascending system and the physiopathology of AD^{1,2}. Noradrenaline (NA)-containing neurons in the locus coeruleus (LC) are the main source of noradrenergic inputs to numerous regions throughout the brain. Due to its widespread efferent innervation, the LC projection system plays a pivotal regulatory role in processes such as stress and maintenance of cognitive performance³. Gannon *et al.* have reported that a significant loss and damage of noradrenergic neurons in LC occurs in AD⁴. Furthermore, O'Bryant *et al.* have suggested an important contribution of noradrenergic LC dysfunction in AD pathogenesis⁵. In this work we present our preliminary results demonstrating that the simultaneous quantitation of 3 catecholamines (CAs) could be a potential new plasma AD biomarkers.

Method: In this retrospective study, we quantified epinephrine, norepinephrine (NE) and dopamine (DA) levels in plasma from patients investigated for neurocognitive disorders (NC), other neurological diseases without dementia (CON), and healthy controls (HC) (Montpellier, Paris). All diagnoses were performed according to current diagnostic criteria including neurological examination, neuropsychological tests, brain MRI and CSF biomarkers. CAs quantifications were performed by HPLC coupled with electrochemical detection. A mathematical model was developed to discriminate AD from other neurocognitive diseases, CON and HC.

Result: Plasma from 202 participants, including 30 AD, were analyzed. A distinctive CAs signature in AD patients was observed comparatively to NC and CON groups. Significant lower levels in epinephrine and NE were observed, whereas DA was increased. A positive correlation between MMSE score and noradrenaline concentrations was observed. This method displays a good discrimination power regarding AD patients with 80 % in sensitivity and 97 % in specificity.

Conclusion: Mathematical scores based on plasma CAs quantitation allowed us to clearly distinguish AD patients from NC and CON. Large prospective studies are needed to confirm that CAs are blood biomarkers for the screening of AD.

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PARALLEL SESSION ABSTRACTS

Diagnosis, treatment and research

Date: Friday, 27 July 2018

5-004

INTERACTIONAL VARIATION IN STANDARDISED COGNITIVE EXAMINATIONS

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Abstract:

The UK's Department of Health suggests that measuring someone's cognitive function is one of the most important assessments clinicians make (DoH, 2015). Cognitive assessments cover a very broad range of activities; they take place in a variety of settings (including primary care, specialist memory clinics, acute care and care homes) and for a variety of reasons (including screening, diagnosing, and measuring change). There is also a wide range of standardized cognitive assessment tools designed to test different aspects of functionality, e.g. Addenbrooke's Cognitive examination (ACE-111), Montreal Cognitive assessment (MOCA) or Six-item Cognitive Impairment test (6CIT). Resources and guidance designed to aid practitioners in their use of these tools often incorrectly assumes a high level of specialist clinical knowledge in administering cognitive assessments. General Practitioners involved in the screening and assessment of dementia have reported that they feel unable to use assessment tools in accordance with appropriate guidelines (Smith, 2015). Additionally research suggests that the interactional practices employed by 'testers' when administering standardized examinations can influence the recipient's responses, their experience of 'being tested'; ultimately test scores become collaborative products of the testing process (Marlaire & Maynard, 1990; Wilkinson, 2013).

We report preliminary results of a study of the communicative and interactional practices exhibited during the delivery of a standardized cognitive assessment tool, the Addenbrooke's Cognitive examination (ACE-R) in a specialist neurology-led memory service. Our initial analyses of the data (video recordings of approximately 80 consultations) demonstrate parallels with Marlaire & Maynard's (1990) earlier findings that suggest there could indeed be 'good reasons for bad tests results' within cognitive examinations. We have begun to find, 1) interactional variability during the introduction of the tests, and within the design of the questions. This variability is evident between different neurologists, and within each neurologist's individual practices in any given consultation; and 2) evidence of interactional non-standardisation, when neurologists diverge from the guidance designed to ensure standardization. This either results from inconsistencies within the guidance itself, or within practices of recipient design. We will report those interactional practices that seem to have an effect on the unfolding of the examination and potentially its outcome.

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PARALLEL SESSION ABSTRACTS

Diagnosis, treatment and research

Date: Friday, 27 July 2018

5-005

ABBV-8E12, A HUMANIZED ANTI-TAU MONOCLONAL ANTIBODY FOR THE TREATMENT OF EARLY ALZHEIMER'S DISEASE: STUDY DESIGN AND BASELINE CHARACTERISTICS FOR A 96-WEEK, MULTIPLE DOSE, RANDOMIZED, DOUBLE-BLIND, PLACEBO-CONTROLLED PHASE 2 STUDY

Kumar Budur¹; Hana Florian²; Deli Wang¹; Weining R Robieson¹; Holly Soares³; Joel B Braunstein⁴; David M Holtzman⁵; Randall J Bateman⁵; Beatrice Rendenbach-Mueller⁶ and Nuno Mendonca⁶, (1)AbbVie, North Chicago, IL, (2)Neuroscience Development, AbbVie, North Chicago, IL, (3)NS Clinical Development, AbbVie, North Chicago, IL, (4)C2N Diagnostics LLC, St. Louis, MO, (5)Washington University, St. Louis, MO, (6)AbbVie Deutschland GmbH & Co. KG, Ludwigshafen, Germany

Table 1. Demographics and Disease Characteristics

Characteristics	N=92
Age, y, mean (SD)	72.1 (6.4)
Sex, n, male (%)	48 (52%)
Race, n, white (%)	88 (97%)
MMSE score, mean (SD)	24.4 (3.0)
RBANS score, mean (SD)	72.8 (10.8)

Abstract:

Objective: ABBV-8E12 is a humanized anti-tau monoclonal antibody currently being developed for the treatment of Early Alzheimer's Disease (AD) and progressive supranuclear palsy (PSP). A phase 1 double-blind, placebo-controlled, single ascending dose study that assessed the safety, tolerability, and pharmacokinetics of ABBV-8E12 in patients with PSP (NCT02494024) was recently completed. The phase 1 results showed that ABBV-8E12, when administered as a single dose up to 50 mg/kg, exhibited an acceptable safety and tolerability profile to support repeat-dose testing in larger cohorts of patients with tauopathies. Here we present the design of an ongoing double-blind, placebo-controlled phase 2 study of ABBV-8E12 in patients with Early AD.

Method: The phase 2, double-blind, placebo-controlled study will assess the 96-week efficacy of ABBV-8E12 in slowing disease progression and its safety in patients with Early AD (NCT02880956). A total of 400 male and female patients, aged 55 to 85 years, will be enrolled at approximately 65 global study sites. Prior to enrollment, patients will have met the criteria for early AD (a Clinical Dementia Rating [CDR]-Global score of 0.5, Mini-Mental State Examination [MMSE] score of 22-30, and a Repeatable Battery for Assessment of Neuropsychological Status [RBANS-DMI] score of ≤ 85) and have had a positive amyloid Positron Emission Tomography scan. Patients will be randomized to one of 3 ABBV-8E12 dose arms or placebo.

Result: The primary efficacy outcome is the CDR – Sum of Boxes (CDR-SB) at Week 96. Key secondary endpoints include, but are not limited to, pharmacokinetic assessment of ABBV-8E12, and the change from baseline to Week 96 for the MMSE, the Alzheimer's Disease Assessment Scale (14-Item) Cognition Portion, and the RBANS. Adverse events will be monitored. Baseline characteristics for the first 92 enrolled patients are presented in Table 1.

Conclusion: A significant unmet medical need exists for the development of disease-modifying drugs for AD which directly impact the biology of the disease and reduce its associated burdens. ABBV-8E12 has shown an acceptable safety and tolerability profile in patients with PSP during phase 1 testing. The current study is designed to evaluate the 96-week efficacy and safety of ABBV-8E12 in patients with Early AD.



PARALLEL SESSION ABSTRACTS

Diagnosis, treatment and research

Date: Friday, 27 July 2018

5-006

RESEARCHING ALZHEIMER'S DISEASE MEDICINES: SETBACKS AND STEPPING STONES

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Abstract:

Objective: Despite large effort and investment by researchers around the world, the quest to develop an effective, disease-modifying medicine to treat or prevent Alzheimer's disease has met many dead-ends. This analysis quantifies and characterizes drugs in the development pipeline in the United States for Alzheimer's disease over the last two decades, including those that are often characterized as "unsuccessful" due to not entering the market as an FDA-approved product for patient use.

Method: The analytical dataset was created using the AdisInsight database, which compiles publicly available information on medicines in development. The study examined drugs indicated for Alzheimer's disease that ended development in clinical trials or regulatory review between 1998 and 2017. A medicine was determined to have ended development if it was categorized in AdisInsight as: "suspended," "discontinued" or "no development reported."

Result: In the past 20 years, four new medicines have been approved for Alzheimer's disease in the United States. In the same period 146 drugs in the pipeline were unsuccessful, resulting in a 2.7% success rate. Fifty-nine of the 146 medicines (40%) ended in phases 0, I or I/II, 57 (39%) in phases II or II/III, 26 (18%) in phase 3 or regulatory review, and 4 (3%) uncategorized clinical development. On average, more than 7 products became inactive per year between 1998 and 2017. Unsuccessful attempts peaked in 2000 (13), 2009 (15), and 2016 (14).

Conclusion: Organizations involved in Alzheimer's drug development have expended a large effort for a relatively small probability of success, reflecting an ongoing commitment despite the complexities of the disease and challenges of the research. Setbacks are inherent in the drug development process and form the basis for ongoing learning. In Alzheimer's disease continued research and investment is needed to overcome the hurdles and meet the needs of people living with this disease.





PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-001

WOMEN'S EXPERIENCE OF THE CAREGIVER ROLE: AN OVERVIEW OF CURRENT FINDINGS

Dr. Annemarie Schumacher Dimech*, Women's Brain Project, Guntershausen, Switzerland

Abstract:

Objective: The aim of this contribution is to present an overview of recent findings about women's experience of their caregiver role. In most societies, the majority of informal/unpaid caregivers (including caregivers of persons living with dementia) are female, usually the wife or daughter of the person needing care. This is mainly due to the endorsed traditional role of women as a natural caregiver as well as demographic factors, such as the fact that in most societies, women tend to have a higher life expectancy than men. In the UK for instance, 60 -70% of caregivers of people living with dementia are women^[1]. This presentation will provide an overview of recent findings while highlighting differences observed between male and female caregivers.

Method: Studies, meta-analyses and reports published in the last five years were included in this literature review. The literature search was conducted using the following terms: "female caregivers", "caregivers" and "female carers".

Result: Most of the literature reported differences in the caregiving experience between women and men. Men tend to seek more instrumental support (e.g. use of day respite care) while women tend to devote more time to active caregiving as well as help out with the more intimate aspects of care (e.g. bathing and using the toilet)^{[1],[2]}. Women are also more likely to reduce working hours or quit their job to take care of their loved one¹. This often leads to long-term financial consequences due to the reduced income as well as the less contributions paid (e.g. pension schemes). This sex- and gender-based disparity in the caregiving role may lead to differences in the quality of the experience and magnitude of the risk for negative outcomes for male and female caregivers. Women tend to report greater caregiver burden as well as more role-conflict, financial consequences and psychological morbidity^{2,[3],[4],[5]} than their male counterparts. Elderly female caregivers were also found to manifest more frailty than male caregivers^[6]. On the other hand, male caregivers are more likely to receive support from their family members than female caregivers.

Conclusion: Gender disparity exists between male and female informal caregivers. This disparity is multidimensional and includes socioeconomic, physical and mental factors where women tend to report more negative consequences linked to their caregiver role. This difference places them at a higher risk for various stress-related health issues such as depression. These differences should be taken into consideration in the formulation of policies as well as the development of strategies and psychoeducational interventions. Gender-specific prevention and support strategies would have an improved potential to meet caregivers' individual needs and reduce risks and negative outcomes.

[1] Alzheimer's Research UK (2015)

[2] Sharma et al. (2016)

[3] Swinkels et al. (2017)

[4] Alzheimer's Research UK (2015)

[5] D'Onofrio et al. (2014)

[6] Santos-Orlandi et al. (2017)



PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-002

GENDER DIFFERENCES IN DEMENTIA CAREGIVING: IMPLICATIONS FOR INTERVENTION

Mary Sherman Mittelman DrPH, Psychiatry, NYU School of Medicine, NYU Langone Health, 145 East 32 Street, Room 509, New York, NY

Abstract:

Objective: To understand gender differences in caregiving. Women are more likely than men to be caregivers. In the US, women provide nearly two-thirds of all elder care, with wives more likely to care for husbands than vice versa and daughters more likely to care for a parent than sons. Research reports that caregiving demands disproportionately fall on working-age women, affecting their ability to work, forcing many to quit their jobs, with associated lost wages and socioeconomic status. Those who stay in the workforce are at risk of absenteeism and lateness that reduces opportunities for job promotions. Women are more likely than men to report that their caregiving responsibilities interfere with their quality of life, including their ability to spend time with friends. Women also report higher burden from caregiving, especially if the care recipient has dementia. Men report less burden and depression than women, who believed caregiving is a female duty. In formal support programs and studies of caregiver services, men are underrepresented.

Method: We examined the differences between male and female spouse caregivers in the baseline data from the original study of the NYU Caregiver intervention (NYUCI), which included 406 caregivers.

Result: While spouse-caregivers of people with Alzheimer's disease, were likely to have played traditional gender roles in their marriages, in the course of dementia caregiving, they were likely to assume tasks traditionally performed by their spouse, leading to the adoption of previously gender-specific roles. Among participants in the NYUCI, female caregivers tended to curtail other activities (i.e., leisure activities) more than male caregivers. Male caregivers received more familial support than female caregivers and also were more likely to hire paid help. Male caregivers were more likely than female caregivers to ask the person they paid to help to perform tasks traditionally performed by their wives, such as cooking and housekeeping, while female caregivers apparently continued to perform homemaking tasks, in addition to the new tasks imposed by their husbands' illness. Male caregivers were twice as likely as female caregivers to receive help from family members, largely from their daughters, and more likely to receive instrumental support, such as help with household chores. Many more female caregivers than male caregivers reported that they received help from no one at all. More wives than husbands were dissatisfied with the assistance they received. Female spousal caregivers reported feeling isolated, suffering from lack of sleep, lack of privacy, being embarrassed by their spouse and feeling rejected by their spouse more frequently than male caregivers. Despite these gender differences, we found that the NYUCI, which is individualized to the needs of each caregiver and family, was equally effective in reducing stress and depression and the physical health impact of caregiving for both men and women.

Conclusion: Studies should explicitly examine gender differences in effects of caregiving and of interventions, rather than just controlling for them in analyses. To be effective, psychosocial interventions for caregivers must take into account the gender differences in roles, attitudes towards caregiving responsibilities and formal and informal support desired, requested and received.



PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-003

IMPROVING QUALITY OF CARE FOR PEOPLE WITH DEMENTIA: WHAT CAN COUNTRIES MEASURE?

Elina M Suzuki, The Organisation for Economic Co-operation and Development, Paris, France

Abstract:

This report presents newly collected data on the quality of dementia care in OECD countries. It finds that while countries have taken important steps to improving care, more must be done to ensure that people living with dementia receive high-quality care that respects their rights and promotes independence. Measuring and comparing the services that are delivered to people with dementia and the outcomes they achieve is a crucial part of improving dementia care. Yet the data infrastructure for dementia remains underdeveloped in most health systems. In this report, we recommend a set of policies that can help countries to improve measurement for dementia and strengthen access to services, care quality, and support for families and carers.





PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-004

THE NATIONAL ALZHEIMER'S AND DEMENTIA PATIENT & CAREGIVER POWERED RESEARCH NETWORK (AD-PCPRN): TRANSFORMING THE CULTURE OF ALZHEIMER'S RESEARCH

MaryAnne Sterling*, Sterling Health IT Consulting, Ashburn, VA

Abstract:

The Alzheimer's PCPRN (AD-PCPRN) is working to connect researchers and people who have, are at risk for having, or care for someone who has Alzheimer's disease or dementia. The AD-PCPRN will focus on developing, conducting, and disseminating patient-centered dementia research. It puts together a phenomenal team led by [USAgainstAlzheimer's](#), the [Mayo Clinic](#), the [University of Florida](#), and the University of California-San Francisco's [Brain Health Registry](#). The Brain Health Registry at UCSF is the cornerstone registry for this project. But others are joining the team, including the Banner Alzheimer's Institute, Cleveland Clinic's Lou Ruvo Center, the Alzheimer's Association's TrialMatch, and Weill Cornell Medicine's AlzU. The project plans to promote collaborations that include other advocacy organizations and industry partners developing diagnostics and treatments for dementia.

The AD-PCPRN is focused on patient-centered comparative effectiveness research (CER). This modality of research investigates what works, for whom, and under what circumstances. It considers the patients' needs and preferences, and the outcomes most important to them. The overarching goal: to help patients and their families make better decisions about their healthcare options.

This AD-PCPRN will enroll large numbers of individuals through existing web-based registries that collect measures of patient cognition over time and self-reported information, such as a patient's or family caregiver's quality of life and responses to interventions. The AD-PCPRN will also refer individuals to clinical trials and facilitate patient-focused studies, including research aimed at reducing burdens on family caregivers.

This is a unique opportunity to encompass the family caregiver as research partner and study the longitudinal impact of caregiving on the health of Alzheimer's and Dementia caregivers, who are predominantly women. According to the [Shriver Report](#), sixty-five percent of all those with Alzheimer's are women and sixty percent of caregivers for persons with Alzheimer's are women. We are well-versed in how Alzheimer's has affected our parent. We frequently have to speak on behalf of our parent(s) who may have lost the ability to recite their medication list or describe the circumstances that led to a fall or illness. These realities make us ideal research partners.

This session will discuss the unique ways in which the AD-PCPRN is engaging dementia family caregivers in clinical research.





PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-005

THE WOMEN'S BRAIN HEALTH INITIATIVE

Lynn Posluns*, Women's Brain Health Initiative, Canada, Toronto, ON, Canada

Abstract:

Despite the discrepancy in rates of disease between men and women, research in Alzheimer's still focuses on male brains. But men and women are different; they differ in the way the disease presents, and how they respond to treatment. We must learn more about those differences to affect better outcomes for both men and women.

To find answers for our daughters, and granddaughters, Women's Brain Health Initiative (WBHI), a Canadian and U.S. charitable foundation launched in 2012, invests in groundbreaking sex-based research, including funding for the first-ever Research Chair in Women's Brain Health and Aging, awarded to Dr. Gillian Einstein at the University of Toronto. The research grant allows Dr. Einstein to build capacity in brain-aging disease research that accounts for gender and sex—that is, social and biological influences—on brain health and aging. This is important to better understand the unique risks for the two sexes, why differences exist, what the different outcomes are and whether they should be treated differently.

WBHI also partners with the Canadian Government funding the Canadian Consortium on Neurodegeneration in Aging (CCNA), a five-year research program aimed at tackling the growing onset of dementia and related illnesses, bringing together 340 of the best and brightest neurodegenerative disease scientists from across Canada. Our funding helps ensure that the brain-aging disease studies take sex and gender into account.

Women's Brain Health Initiative is a significant force in raising critical awareness of the unacceptable discrepancies in brain research on afflictions that present in women in frightening proportions. WBHI's education and awareness programs are critical to improving women's brain health and to catalyzing the urgency that must drive funds towards research to combat brain aging diseases that affect women. Women are almost half our work force and are our primary caregivers. Their good health drives our families, our communities and our economy.

While we actively engage in scientific discovery for tomorrow, WBHI makes every effort to ensure we protect the women in our lives by educating them and ourselves – on the best ways to stave off brain disease progression. We share the research findings in order to give the public access to the most current thinking on ways to stay cognitively healthy for as long as possible. Mounting evidence indicates that maintaining a healthy lifestyle can delay or prevent some dementias and the earlier you start, the stronger the protective effect will be. We hope that through better education, people start thinking about protecting their brain all through their life.

To provide the best ways to maintain cognitive vitality, Women's Brain Health Initiative produces several education programs, including its popular MIND OVER MATTER® magazine. MIND OVER MATTER® (MOM) magazine is an informative resource publication created and produced by Women's Brain Health Initiative on the best evidence-based ways to protect your brain health. MOM magazine advocates healthy living, brain health awareness, improved brain research/study, and 'self-care.' The articles are educational and inspiring and a practical resource for maintaining healthy minds. The magazine communicates scientific evidence-based information in a way that is concise and carefully worded so that it is easy to understand. The scientists and studies referred to are both relevant and applicable to the lives of women globally.



PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-006

FEMALE CAREGIVERS' PERSPECTIVES ON THE MOST IMPORTANT OUTCOMES OF ALZHEIMER'S DISEASE AND DEMENTIA

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Abstract:

Objectives: The primary objective was to identify which outcomes of Alzheimer's Disease (AD) matter most to key stakeholders based on a combination of evidence gathered through a systematic literature review (SLR), surveys and face-to-face workshops. Here, we report findings from the perspective of female caregivers.

Methods: This study employed multiple research methods. An SLR sought all available evidence which directly elicited the views of stakeholders. Four databases of health and social care related publications were searched, including research in any language. Subsequently, a survey was distributed through electronic mailing lists, e-newsletters and social media platforms across Europe and in print via memory clinics in the UK. It is collecting quantitative data on the relative importance of outcomes.

Results: From the 32 studies identified in the SLR 23 studies, conducted in eleven countries, provided caregiver perspectives on AD outcomes of importance. The studies utilised mainly surveys, interviews and focus groups to gather information. Approximately 2,050 individuals were involved in these studies, of which, 62% were female caregivers. Data from female caregivers could be extracted from eleven studies. Twenty important outcomes emerged. These can be summarised within overarching themes of cognition; functioning; behavioural & neuropsychiatric symptoms; impact on the caregiver; patient quality of life; social issues and health/social care & treatment. The most frequently recurring outcomes are listed here with an example of the evidence in one of the participant's own words: patients' independence & autonomy (*"I don't want to ever make him feel like he is less of a person"*); patient mental health (*"it's quite easy for him to slip into a depression"*); the impact of stigma (*"I wasn't used to the looks people gave me when I would take mom out"*); caregiver burden (*"I felt guilty and overwhelmed and I felt frustrated people didn't understand"*); and lack of access to health services and disease information (*"the communication has been really poor... you feel, well they've told me that and they're just letting me get on with it"*).

Findings from female caregiver participants in the survey are pending. They will add further depth to the findings from the SLR by indicating the prioritisation of outcomes of AD or dementia according to women caring for loved ones at different stages of the disease. They will be available for discussion in detail at the conference.

Conclusion: This mixed methods study is ongoing. Findings from the SLR indicate a range of clinical, practical and personal outcomes that female caregivers of people with AD find important. The full set of outcome domains and their relative priority to stakeholders will emerge when all findings are synthesised.

Acknowledgement: This work has received support from the EU/EFPIA Innovative Medicines Initiative 2 Joint Undertaking (ROADMAP grant n° 116020).



PARALLEL SESSION ABSTRACTS

Women and dementia

Date: Friday, 27 July 2018

6-007

DEMENTIA AND GENDER EQUALITY - AN UPDATE FROM THE WOMEN'S BRAIN PROJECT

Maria Teresa Ferretti^{*}, Women's Brain Project, Zurich, Switzerland

Abstract:

Dementia takes a double toll on women, inflicting a disproportionate burden on them both as patients and as caregivers. On one hand, 60-70% of dementia patients are women; in the US alone, 4.2 million women live with the condition. In spite of such striking statistic, sex and gender are rarely considered when designing pre-clinical experiments (mostly run in male mice) and analyzing the results of clinical trials (rarely stratified by sex). On the other hand, women represent 70% of the informal caregivers to demented patients; however, the impact of women's caregiving burden on the economy and society (in terms of work-force loss and family distress) is often neglected.

The Women's Brain Project (WBP), an international non-profit organization based in Switzerland, was founded in 2016 to advocate for sex and gender consideration in the prevention, diagnosis and treatment of mental and brain diseases, including dementia.

In this talk I will offer an overview of our current understanding of the topic of sex and gender in Alzheimer's disease and the position that WBP has taken with respect to this issue. The talk will describe the activities that the WBP has spearheaded in the first two years since its inception to raise awareness in the scientific community and the civil society on this topic. The main outcome of WBP's scientific and outreach activities will be briefly summarized. The existing network of international collaborations will be highlighted and possibilities for further collaborations with stakeholders will be presented. I will conclude with a discussion of the biggest challenges ahead of us, especially in terms of gender inequalities in care and caregiving, and how novel technologies could offer new ways to support women's mental health as patients and as caregivers. This is a call of action to scientists, regulators, pharma industries and policy makers; eventually, it will take the concerted action of all sectors of the society to bring gender equality in dementia.





PARALLEL SESSION ABSTRACTS

Well-being and quality of life

Date: Friday, 27 July 2018

7-001

LETTERS TO MY GRANDPARENT: THE SILVER LINING OF A DEMENTIA DIAGNOSIS IN GRANDCHILDREN-GRANDPARENT RELATIONSHIPS

Alexandria R. Ebert*; Anca M. Miron; Amy E. Hodel; Rachel A. Davis; Sarah K. Rowley and Emma Melotik, University of Wisconsin Oshkosh, Oshkosh, WI

Abstract:

Objective: Grandchildren have a strong motivation to maintain their relationships with their grandparents with dementia, despite the interaction challenges that arise (e.g., Giarusso, Feng, Silverstein, & Bengtson, 2001; Miron, Thompson, McFadden, & Ebert, 2017). In order to accommodate to the grandparents' memory and communicative difficulties and to maintain a meaningful relationship with them, young adults utilize specific verbal and non-verbal interaction strategies, which involve the use of perspective taking, vigilance, and knowledge (Miron, Thompson, Ebert, & McFadden, 2017). Young adults may use *differential* interaction strategies with grandparents with dementia compared to those without dementia. Perspective taking may be a particularly useful strategy for grandchildren because of its positive outcomes, such as increased empathic concern for the other (Batson, 2011). We examined the differences in perspective taking between young adults with grandparents who have dementia, compared to those with grandparents without dementia using Bertacco and Deponte (2005)'s letter-writing and free-recall tasks. Perspective taking was operationally defined as higher number of 2nd person singular pronouns (Miron, Kulibert, Saltigerald, & Petrouske, 2017) and as higher number of self-reported shared experiences in the letter written to the grandparent (Bertacco & Deponte, 2005). Perspective taking was also measured using Miron, Thompson, Anderson, Bagley, Melotik, & Rowley (2017)'s Perspective-Taking Orientation Index (5 items; $\alpha=.90$). We also assessed the presence or absence of empathic concern (mentions of compassionate, softhearted, warm, tender, sympathy, and moved; Batson, 2011) and solidarity (mentions of explicitly/implicitly love, longing/missing, gratitude, etc.).

Method: College students with a grandparent diagnosed with dementia (DD group; $N = 22$) or a grandparent without dementia (ND group; $N = 45$) participated in the study. Participants completed three tasks: (1) 15-minute letter-writing task, in which they wrote a letter to a designated grandparent, (2) 5-minute free-recall task, in which they wrote down as many shared experiences with and/or personality traits of their grandparents as possible, and (3) an untimed questionnaire containing the perspective taking measure, and grandparent and personal demographic measures. Researchers then coded the letter-writing and free-recall tasks for perspective taking, empathic concern, solidarity, and shared experiences.

Result: Participants in the DD group reported experiencing higher perspective taking ($p = .027$), used more second person pronouns ($p = .002$) and showed more empathic concern for their grandparent in their letters than those in the ND group ($p = .016$). Participants did not significantly differ in solidarity ($p = .13$) or in number of shared negative experiences ($p = .45$). Participants in the DD group did, however, report more shared positive experiences in their letters than the ND group ($p = .007$).

Conclusion: These findings are consistent with Miron et al. (2017)'s verbal and non-verbal dementia interactions model, which specifies that young adults engage in perspective taking to maintain a relational presence with their grandparent who has dementia. Our results suggest that young adults utilize different interaction strategies when interacting with a grandparent who has dementia compared to young adults interacting with a grandparent without dementia.

PARALLEL SESSION ABSTRACTS

Well-being and quality of life

Date: Friday, 27 July 2018

7-002

FROM STRANGERS TO FRIENDS: BENEFITS OF INTERGENERATIONAL BONDING PROGRAMME FOR PRESCHOOLERS AND ELDERLY WITH DEMENTIA

Jia Yun Chng*; Kimo Ong and Siti Arsat, Psychosocial, Apex Harmony Lodge, Singapore, Singapore

Abstract:

Apex Harmony Lodge (AHL) is the first purpose-built home for people with dementia in Singapore, providing services for residents in long-term residential care. Aligned to the philosophy of Person-Centred Care (PCC), AHL provides integrated, holistic and enabling care with social psychology as one core component as we value the importance of building positive relationships for our residents.

Research has shown that Intergenerational Bonding Programmes (IGBP) enhanced the quality of life of people with dementia as they experienced an increase in positive emotional well-being, reductions in social isolation and a greater sense of purpose.

Since 2015, AHL has worked in partnership with like-minded partner, Church of Holy Trinity Kindergarten (CHTK) to co-create and implement IGBP for preschoolers and residents. The intent was to enable both generations to interact, learn from and with one another and appreciate the strengths of each other. The approach is to conduct meaningful, interactive activities, providing shared opportunities for relationship building. For CHTK, this collaboration is part of the values and character building curriculum. Teachers conduct pre-session lessons weekly, emphasizing values such as respect and familiarising preschoolers with the activities, to empower them to guide residents during sessions.

A total of 228 preschoolers aged 5 to 6 years old and 36 residents participated in 63 IGBP sessions from 2015 to 2017. Upon review, Bradford Well-being Profile was used to document observations of residents to evaluate their well-being after each session in 2017. This includes qualitative notes on behaviour, mood and engagement. Feedback from CHTK about IGBP was collated through videoed interviews with preschoolers and teachers which were transcribed with consent. Parents' observations of preschoolers were collated via a feedback form. Additionally, interactions between residents and preschoolers were observed and documented after sessions by facilitators to detail the process of intergenerational bonding. Thematic analysis was used to examine residents' well-being, preschoolers' learning from IGBP and intergenerational bonding.

This presentation will share benefits accrued such as positive well-being experienced by residents including pleasure and enjoyment, a sense of purpose in being able to use their remaining abilities to engage in the interactive activities with the preschoolers and showing warmth and affection towards them. IGBP benefitted preschoolers as it provided them with a learning platform, allowing them to discover more about themselves through stepping beyond their comfort zones. Preschoolers were observed to have transferred their learning from IGBP into daily lives, applying skills learned during IGBP while interacting with others. Challenges encountered and recommendations to improve IGBP will also be discussed.

The process of building a relationship does not happen overnight. Results showed that although preschoolers were apprehensive in initial interactions with our residents, IGBP provided constant opportunities for them to meet and they began to enjoy interactions after familiarising with each other. Interchangeable roles as mentors and mentees during interactions enhanced their rapport when they used strengths to complement each other. Coupled with support provided by facilitators and teachers, intergenerational bonds were formed with mutual attachment between residents and preschoolers.





PARALLEL SESSION ABSTRACTS

Well-being and quality of life

Date: Friday, 27 July 2018

7-003

GOOD SPIRIT, GOOD LIFE: A QUALITY OF LIFE TOOL FOR ABORIGINAL AUSTRALIANS WITH COGNITIVE IMPAIRMENT AND DEMENTIA

Kate Smith¹; **Lianne Gilchrist¹**; Dawn Bessarab Prof²; Dina LoGiudice Dr³; Leon Flicker Prof⁴; Julie Ratcliffe Prof⁵; Christine Clinch Dr²; Paula Edgill Dr² and Kevin Taylor Mr², (1)Centre for Aboriginal Medical and Dental Health, University of Western Australia, Perth, WA, Australia, (2)Centre for Aboriginal Medical and Dental Health, University of Western Australia, Perth, Australia, (3)National Ageing Research Institute, Melbourne Health, Melbourne, Australia, (4)Western Australian Centre for Health and Ageing, University of Western Australia, Perth, Australia, (5)Institute for Choice, University of South Australia, Adelaide, Australia

Abstract:

Objective: Enhancing quality of life (QoL) is of central importance for people living with dementia and a key outcome measure for service providers and researchers in aged care. Currently, there is no tool to evaluate QoL from the point of view of older Aboriginal Australians. This study aims to develop such a tool for older Aboriginal Australians with dementia.

Method: The study is being conducted in Perth, Australia. The use of a Participatory Action Research (PAR) approach ensures Indigenous worldviews are embedded in the co-design, analysis and dissemination of the research findings. Purposive sampling has been utilised to ensure Australian Aboriginal participants represent a range of ages, family groups and gender. Data was collected through interviews and yarning circles and analysed thematically.

Results: *Most participants preferred the term "a good life" to describe QoL. Interviews were conducted with 22 Aboriginal participants aged 47-82 years, predominantly women (68%). Following analysis of interview transcripts, 12 main themes were identified: community, family, culture and identity, eldership, services, religion, friends, country, self, health, healing and supports and future planning. Four yarning groups comprised of advisory group members and interview participants were conducted and draft questions for the tool developed encompassing the above themes.*

Conclusion: The factors important to the quality of life of older Aboriginal Australians are culturally, socially, spiritually and environmentally constructed, according to the literature and findings in this study. The Good Spirit, Good Life draft tool is the first of its kind for older Aboriginal Australians with dementia. Further validation is underway in two Australian cities.





PARALLEL SESSION ABSTRACTS

Well-being and quality of life

Date: Friday, 27 July 2018

7-004

OLDER PEOPLE WHO 'CALL OUT' REPETITIVELY IN THE ACUTE HOSPITAL: TOWARDS A USEFUL INTERVENTION

Jessica L Beaver¹; Sarah E Goldberg Dr¹; Rowan H Harwood Prof² and Alison Edgley Dr¹, (1)School of Health Sciences, The University of Nottingham, Nottingham, United Kingdom, (2)Health Care of Older People (HCOP), The Queen's Medical Centre, Nottingham, United Kingdom

Abstract:

On acute Medicine for Older People hospital wards, staff often care for patients with cognitive impairment who 'call out' repetitively. This consists of disruptive vocal behaviours, such as constant screaming, asking repetitive questions or making demands, and bizarre noise-making. This behaviour, combined with acute hospital admission and busy, unfamiliar staff, can cause serious effects on the quality of care provided for people who call out in the acute hospital setting. It can lead to staff frustration and avoidance, leaving these patients potentially neglected. There are a number of reports in the literature regarding calling out in nursing homes, however there is very little empirical evidence in the context of the acute hospital. Little is currently known about knowledge or beliefs surrounding this behaviour, and how hospital staff and carers respond to it.

The aim of this study was to discover observed and reported challenges surrounding people who call out repetitively in the acute hospital, in order to propose an intervention to enhance patient care and wellbeing.

A mixed-methods study was conducted across seven wards on two acute hospital sites. An ethnographic case-series of 30 older people who call out were examined. This utilised observations with field notes, family and staff interviews, records of nursing documentation, and baseline and ongoing quantitative measures. The process was iterative, allowing for development throughout the data collection process. Qualitative and quantitative data were analysed using inductive thematic analysis, and descriptive statistics respectively.

On average, participants had poor mobility and functional ability (Barthel ADL Index; Collin et al. 2009), had severe cognitive impairment (SMMSE; Vertesi et al. 2001), and were deemed likely to have delirium (DRS-R-98; Trzepacz et al. 2001).

It was found that staff often believe that some patients who call out repetitively, will continue to call out "no matter what" the staff members action. We refer to this phenomena within an otherwise caring environment as 'Socialised Care Futility' (SCF). This was found throughout observation, interviews, and records of nursing documentation. Rationalisations are used by staff to justify SCF, such as calling out being unrelated to expressions of need, or being a symptom of dementia, and the assumption of lack of insight by the person calling out ("they don't know they're doing it"). SCF is underpinned by two 'protective' social mechanisms for staff: against negative internal perceptions of professional identity and personal morality. Staff report that they get "quicker" at identifying if intervening with a patient is futile, potentially increasing the risk of 'real' needs being overlooked in the hospital.

These findings can help us to better understand the cognitive and functional abilities of people who call out repetitively within the acute hospital; alongside recognising why and how staff members in the acute hospital rationalise avoiding their patients who are calling out. This research can help us to develop an intervention for use in the acute hospital. To improve patient care and wellbeing, we propose a systematic and comprehensive list of short and simple day-to-day interventions for staff to implement.



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Well-being and quality of life

Date: Friday, 27 July 2018

7-005

COMMUNICATION HELPS FOR A BETTER LIFE WITH DEMENTIA

Mrs. Sabine Henry-Gössing*, Ligue Nationale Alzheimer Liga ASBL/VZW/VoG, Bruxelles, Belgium

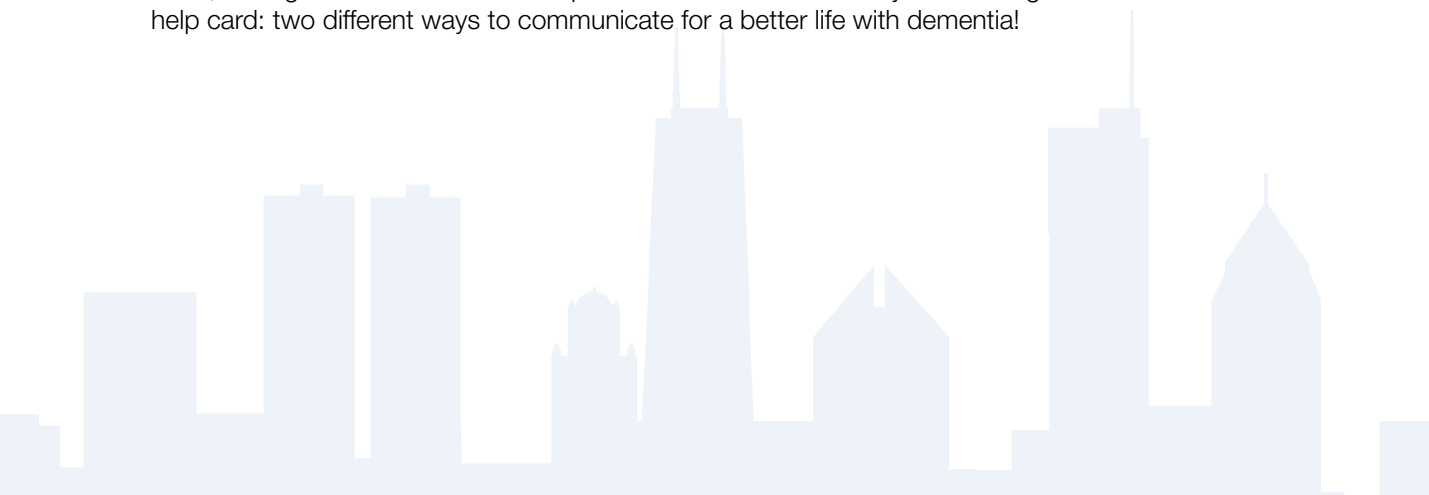
Abstract:

Since 2003, *Ligue Alzheimer ASBL* has been organizing *Alzheimer Cafés* for carers and people with dementia. Actually, there are about 50 *Alzheimer Cafés* in the French-speaking part of Belgium.

Via the national helpline 0800 15 225 in Belgium, the psycho-social department got a lot of questions from carers who weren't able to participate to any *Alzheimer Café* because of the schedule of the activity. The carers are indeed still active in their professional life and can't be present from 2pm to 4pm at the *Alzheimer Café*. Therefore, how can we help them? How to offer support to these carers, and also, at convenient times? The *Ligue Alzheimer ASBL* created the Virtual *Alzheimer Café* with the collaboration of the IT Department of the Catholic University of Louvain-la-Neuve. This is a new free platform, accessible via the Internet, allowing everyone who wants to participate at an *Alzheimer Café*, from home, behind a computer screen. On this secure platform, sessions will be proposed in the morning and in the evening. From his own computer, each participant will be able to interact with others and with the animator. The objectives remain the same as a classic *Alzheimer Café*: to bring people concerned by Alzheimer's disease (or other forms of dementia) together, to encourage the exchange and the expression of experiences, to support and to provide information and reflection. A few months before the launch of this activity, the *Ligue Alzheimer ASBL* proposed a survey of a dozen questions to its future public. These questions were about time, duration, frequency, type of audience, subjects and so on. Based on the answers, the conditions of use were determined. The initiative was officially launched in January 2018.

Another novelty set up in parallel is the help card. This help card comes from a think tank of "The fighters" groups composed by younger onset dementia and their carers. They think about daily and social life and ways to improve their quality of life with the disease. In this context, they suggested the creation of the help card. The purpose of this card is twofold: firstly, it can be used to discretely mention that the fighter has Alzheimer's disease. Indeed, this person may have an unusual behavior. For instance, one member of the group is in a shop, at the restaurant with his carers. He might be agitated, or might talk loudly... The carer can then show the card to inform the waiter of the disease of his companion. Secondly, this card can be useful if the fighter walks alone, get lost, has an accident, and so on. The card informs that he has dementia and furthermore, mentions an emergency contact number. The final purpose of this card is to make fighters's social life easier and safer.

To conclude, on one hand, these initiatives meet the needs of those concerned by dementia and on the other hand, the *Ligue Alzheimer ASBL* adapts itself to the actual society and the digital era. Virtual *Alzheimer Café* and help card: two different ways to communicate for a better life with dementia!





PARALLEL SESSION ABSTRACTS

Well-being and quality of life

Date: Friday, 27 July 2018

7-006

SOMEBODY STOLE MY MOTHER!

Violet Okech-Helu Dr*, Kenyatta National Teaching and Referral Hospital, Nairobi, Kenya

Abstract:

This is a story of Turfena: a dementia care-giver's journey in taking care of Nora: her beloved mother-in-law who was diagnosed with dementia, in a rural setting in Africa, in the late 1960's. They share the lessons learnt as a family and a community.

"O tall one, have you come to visit?" -the beautiful, light skinned African woman with work worn hands asked her eldest son, Alfayo. "Yes, Mother, I have come to see you," Alfayo replied, the pain in his voice unmistakable.

It pained him that his dear, once vibrant and energetic mother could not remember him. She had forgotten who all her family members and neighbours were. Everyone, except Turfena, his wife. However, Nora still showed traces of her legendary fiery temper, if you tried to stop her from going to collect firewood for the family. At least, parts of the mother he had known were still intact, he mused.

Fortunately, the whole family and village retained the memory of the generous, wise and industrious Nora, in their hearts and minds. They gently helped bring her back home, when she went out to gather firewood but could not remember the way back home. Turfena would gladly receive her and give her a dish of her favourite meal. Thank God too, that Nora still enjoyed shelling maize, their staple food, as she hummed long forgotten songs to herself. That could keep her busy at home for hours and avoid her getting lost, again. He remembered how for many years, she had walked barefoot for many miles to buy paraffin and then return to their village to sell it in small quantities to their neighbours. For his education.

She vigorously went about her many duties as a young wife and mother-to ensure her children got food and clothing with the help of Daudi, her husband.

The paraffin she sold helped light firewood for their meals and the small flickering "Nyangile" tin lamp. The lamp complimented the warm glow from the cooking fire, spindly sticks of firewood stuck between three stones and a pot, in her smoky kitchen. Her children learnt many ancient folk tales (sigendni) from her, passed on from generation to generation, by the light of that small lamp.

Nora had dreamt of Alfayo and his siblings going to school and having a bright future. The young Alfayo excelled at school and looked forward to allowing Mama to rest from her endless chores once he secured a job. She blessed him, when he brought his first pay check home.

The changes in Nora crept in slowly, a few years after their father, Daudi, died. Initially they thought that she was still mourning her husband, when she seemed withdrawn and forgetful. Then she started giving back the wrong amount of money in change, for paraffin. That was strange; Nora had a fantastic memory and did all her sums mentally. Next was concern that someone had stolen some of the teacup. When her daughter Margaret went to check on the cups, there they were, neatly stacked in her kitchen cupboard. When she started forgetting her way back home, from collecting firewood, they realized something was very wrong.

Dementia was trying to steal their beloved mother.

They resolved to give her the best loving care, preserve her dignity and help her still enjoy what she loved doing.

Dementia care-givers experience many challenges and losses- emotional, social and physical - as we care for our loved ones and many intangible rewards too. All this however, cannot compare with the joy of knowing that though people living with dementia may not remember who they are, we do remember who they are and we care.



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Nora, dementia tried to steal you from us, but your legacy lives on, in our hearts and minds, Amen.

Diverse populations - inclusion and equality

Date: Friday, 27 July 2018

8-001

FROM SELDOM HEARD TO SEEN AND HEARD: ADAPTING SUPPORT TO SUIT THE NEEDS OF PEOPLE AFFECTED BY DEMENTIA FROM SELDOM HEARD GROUPS

Kelly Kaye, Dementia Action Alliance, London, United Kingdom

Abstract:

The Dementia Action Alliance (DAA) is a membership body and independent network of over 150 health and social care organisations in England to connect, share best practice and take action on dementia. They support its members to work in partnership, and inspire each other to adopt new practices that radically improve the health and social care outcomes of people affected by dementia. One such means is through its campaigns.

After surveying their members to find out what they wished the DAA to campaign on, the deciding vote was post diagnostic support for people from seldom heard groups. Based on the survey results, research was carried out by the DAA Secretariat around dementia and prisons, LGBT, and Learning Disabilities; with the aim to formulate a set of recommendations that organisations and individuals could action to support these groups. This was achieved by holding roundtables to kick-start the campaign, which were attended by people affected by dementia and experts in the field of prisons, LGBT, and Learning Disabilities. The attendees created a set of recommendations for people to implement to support people affected by dementia from these three groups and include:



- For those with a learning disability, health professionals need to tell the person the diagnosis and say the word dementia; the diagnosis needs to be understood
- For those in prison, training needs to be available to help staff identify when a prisoner is presenting symptoms of dementia or other forms of cognitive impairment
- For those in the LGBT community, organisations to create links with local services for the LGBT community and opportunities for shared working



PARALLEL SESSION ABSTRACTS

The DAA then officially launched the *From Seldom Heard to Seen and Heard* campaign at an event that saw people affected by dementia from seldom heard groups discuss the extra support that is required for these groups and what more they would like to see. It saw experts present their research and attendees discuss in groups what more could be done to support seldom heard groups. In addition to the three aforementioned groups, delegates discussed other proposed seldom heard groups and some solutions for these.

The campaign shows that there are many seldom heard groups, ones that people may not be aware of. The needs and complexities of these groups can be different and therefore it is important for people to be aware that a one-size-fits-all approach to supporting people affected by dementia will not work.

The campaign is still running and its objectives are to raise awareness of the challenges faced by people with dementia from seldom heard groups, influence system-wide change, and bring about organisational change by implementing the recommendations. The DAA are asking members to pledge to take action and to share the results with the DAA, regardless of the seldom heard group they are supporting. Members are also encouraged to share case studies, which will be made available on the DAA website.

The campaign has already seen a great deal of success including MP Caroline Flint reference the DAA, pointing out that there was no national strategy for dementia in prisons. This resulted in Secretary of State for Justice, Sam Gyimah MP establishing a working group. The DAA have liaised with Attitude magazine and the CEO of Stonewall in regards to writing articles. We have been working with MacIntyre, a leading disability charity to support each other to make changes to each other's work to make things more accessible for both people with dementia and also for people with learning disabilities.





PARALLEL SESSION ABSTRACTS

Diverse populations - inclusion and equality

Date: Friday, 27 July 2018

8-002

MILWAUKEE MELODIES AND MEMORIES CHORUS PROJECT: THE AMAZING GRACE CHORUS: DEVELOPING A CULTURALLY-TAILORED LIFESTYLE INTERVENTION PROGRAM FOR AFRICAN AMERICANS WITH DEMENTIA AND CAREGIVERS USING AN ASSET-BASED COMMUNITY DEVELOPMENT APPROACH

Gina Green-Harris MBA¹; Sheryl L Coley DrPH²; **Stephanie Houston MBA³**; Nia Norris MA¹ and Dorothy Edwards PhD⁴, (1)Wisconsin Alzheimer's Institute, Milwaukee, WI, (2)Wisconsin Alzheimer's Institute, Madison, WI, (3)UW Madison, Wisconsin Alzheimer's Institute, Milwaukee, WI, (4)Wisconsin Alzheimer's Disease Research Center, Madison, WI

Abstract:

Alzheimer's disease and related dementias (ADRD) persist as a public health crisis, particularly for African-American communities. Furthermore, barriers continue for African-American family members accessing care and support for their loved ones who receive a diagnosis. Experiencing these barriers can lead to increased caregiver burden and stress, and more isolation for persons living with ADRD because of stigma and sociocultural and structural factors unique to elders of color and their families.

Through an Asset Based Community Development (ABCD) approach, the Wisconsin Alzheimer's Institute Regional Milwaukee Office developed a multi-level outreach program providing advocacy, education & treatment to African-American elders and care partners. As one objective, increased access to diagnostic evaluation, services, and referral to programs is given through a federally qualified health center memory diagnostic clinic. As an integral extension of this outreach program, the Milwaukee Melodies and Memories Chorus Project (The Amazing Grace Chorus) was initiated in 2014 to specifically meet the needs of African-American elders with ADRD and their families through musical opportunities for impactful cognitive stimulation, social engagement, ongoing dementia education and coping strategies, and connecting families to ongoing services. The chorus completes 2 14-week seasons per year and each season concludes with a community concert. Our ABCD approach integrates community engagement principles throughout the development of this chorus; professional Milwaukee-based conductors, including one living with dementia, lead this chorus while incorporating continuous insight from the chorus members and their families.

The 30 chorus participants include 60% with ADRD with the rest of the participants being family members. The chorus is majority female (55%), and the average age of chorus members with ADRD is 83 years (82.6±8) with younger family members (62±6). Chorus members complete standardized assessments to evaluate impact of Chorus participation on Quality of Life (QoL) and Self Esteem. Results indicate that at the conclusion of each 14-week season, participants reported improved global QoL (70%) and increased self-esteem (70%) represented by improvements in self-worth (60%), decreased perceptions of failure and uselessness (40%). In addition, participants report increased participation in physical activity (60%) increased engagement in community activities separate from the chorus (45%), and improvements in communication between family members at home (55%). According to family members, chorus participants with ADRD have also reported improved mood, feeling more included within their families, and increased confidence in going out into public settings beyond the chorus rehearsals.

The Amazing Grace Chorus project is an early stage, promising program demonstrating potential for effectiveness in helping persons with ADRD and their family members with improvements in self-esteem, reduction of isolation and stigma, and building social support for families in a culturally-tailored manner. The Chorus has become more ethnically diverse over time and the number of performances has expanded from two in 2014 to six in 2017. The Chorus provides an important opportunity for meaningful community engagement and social support as well as a powerful means of confronting negative stereotypes about African-American individuals with ADRD.



PARALLEL SESSION ABSTRACTS

Diverse populations - inclusion and equality

Date: Friday, 27 July 2018

8-003

ANCESTRY BACKGROUND: IMPLICATIONS FOR COGNITIVE DECLINE AND MORTALITY IN DEMENTIA

J Jesus Llibre*, Global Brain Health Institute., La Habana, Cuba; Dr. Juan J Llibre Rodriguez Dr., Alzheimer's Research, Medical University of Havana, La Habana, Cuba and Ana M Rodriguez Salgado, National Institute of Neurology, La Habana, Cuba

Abstract:

Background: Population ageing will lead to a dramatic increase in dementia prevalence and incidence across all world regions. Much of the increase will take place in low and middle-income countries (LMICs). However, our understanding of Alzheimer's disease is limited by the characteristics of the populations who have traditionally been included in investigations. Most of the risk factor has been identify in studies including Caucasians and participants leaving in High Income Countries. These create a relevant priority to better understand variations in prevalence, incidence and risk factors of dementia among diverse and admixed populations living in LMIC.

Objective: The present study aims to identify the effects of ancestry background (genetic admixture) on cognitive decline and dementia mortality.

Methods: In an admixed population of older Cubans we explored the effects of ethnic identity and genetic admixture on APOE genotype and its association with dementia prevalence, incidence and cognitive decline. We conducted a two phase population-based study among residents aged 65 or more in different seven areas of Cuba. Baseline data was used to estimate the effect of ancestry background and cognitive status. The second wave (incidence wave) was conducted 4.5 years after cohort inception in order to estimate effect of ancestry background on cognitive decline and mortality rate. Dementia diagnosis was established using 10/66 Dementia and DSM-IV criteria. Genetic admixture was determined in 235 dementia cases and 349 controls.

Results: The prevalence of dementia was 10.8% according to the 10/66 criteria. Dementia was associated with older age, less education, a family history of dementia, shorter leg length and smaller skull circumference. The incidence rate of 10/66 dementia was 21 per 1000/year (95% CI, 17.6-23.5). The overall APOE association with dementia prevalence was 3.38 (CI 95% 2.48-4.60). After controlling for age, sex and education, African admixture was not associated with dementia (PR contrasting 100% African with 100% European admixture 1.44, 95% CI 0.73-2.84). After extending the model to include the interaction between APOE genotype and African ancestry, we showed the effect of any APOE e4 allele would vary continuously from PR 2.51 (95% CI 1.11-5.68) in those with European ancestry to 1.12 in those with pure African ancestry.

Conclusions: We found no evidence of a direct effect of admixture on mortality rate. After controlling for age, sex and education African Ancestry was not associated with a higher. This study highlight that the higher rate of Dementia in African Americans may be driven mainly by health and social disparities.



PARALLEL SESSION ABSTRACTS

Diverse populations - inclusion and equality

Date: Friday, 27 July 2018

8-004

SCRUTINIZING ACCESS TO DEMENTIA INFORMATION, DIAGNOSIS AND SUPPORTS FOR PUNJABI AND KOREAN COMMUNITIES IN CANADA

Sharon D Koehn^{*1}; Morgan Donahue Ms.¹; Neil Drummond Dr²; Fabio Feldman Dr³ and Min-ah Cho Ms¹, (1) Gerontology, Simon Fraser University, Vancouver, BC, Canada, (2) Family Medicine, University of Alberta, Edmonton, AB, Canada, (3) Patient Safety and Injury Prevention, Fraser Health, Surrey, BC, Canada

Abstract:

Objective: The Building Trust project aimed to understand the process of gaining access to dementia-related information, diagnosis, care and psychosocial supports by Punjabi- and Korean-speaking older adults with Alzheimer's Disease and related dementias and their informal caregivers living in the Fraser Health region of British Columbia, Canada.

Method: Semi-structured face-to-face interviews were conducted with 15 dyads of persons with dementia (PWD) and their informal caregivers (10 Punjabi; 5 Korean). The PWD and caregiver were interviewed separately to explore their experiences of the PWD's dementia journey. Additionally focus groups with older men, older women, and working age men and women were held within each of the Punjabi and Korean communities (N=6 focus groups). These community members helped us to understand more broadly what older adults and people of their children's ages know and believe about dementia and the available supports.

Result: Culturally mediated views of aging and illness in combination with low levels of education and literacy sometimes served as barriers to recognition of behaviours as symptoms of dementia requiring medical help. Limited understanding of dementia in both communities contributed to stigmatization of the disease. Family involvement can add barriers or introduce opportunities and benefits for dementia diagnosis and care, but some participants, especially in the Korean community, indicated that adult children were not always readily available to locate services, and provide much-needed transportation and interpretation. Koreans were more likely than Punjabis to have access to computers and seek out information on the internet, but there were fewer services in the community for Korean speakers, compared to those for Punjabis. Participants identified Punjabi temples and Korean churches as important sources of influence through which dementia information could be conveyed.

Conclusion: Use of the Candidacy Framework to break down the process of access revealed that intersections of cultural and systemic barriers disadvantage these two immigrant communities in ways specific to each. While migration introduces common challenges, the distinct profiles of each cultural group engender important differences, underscoring the importance of recognizing both the heterogeneity of immigrant older adults and the systemic challenges that marginalize them.





PARALLEL SESSION ABSTRACTS

Diverse populations - inclusion and equality

Date: Friday, 27 July 2018

8-005

THE LIVED EXPERIENCE OF DEMENTIA IN MĀORI COMMUNITIES

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Abstract:

Objective: There is a paucity of literature concerning Māori (Indigenous people of New Zealand), and dementia. As a result dementia care pathways in New Zealand are predicated on a western concept of dementia. The first objective of this research is to develop a Māori theory of dementia which will inform and facilitate improvement in existing approaches to the treatment, and management of dementia for Māori. The second aim of the research is to use that knowledge base to inform the development of a Māori-responsive assessment tool for the diagnosis of dementia.

Method: We conducted 14 wānanga (focus group interviews) with older Māori at 7 locations throughout New Zealand, 8 interviews with whānau (family) care partners and 3 interviews with individual elders. Interviews were semi-structured. A traditional Māori research analysis (Mahi Roopu), a collective Indigenous approach that guides the process of constructing the themes, and a grounded theory approach were utilised to compare transcripts for similarities and differences.

Results: Eleven major themes have been identified from the data. However, in searching for points of difference from the existing knowledge base, the following 4 themes were identified as being additional characteristics of how Māori understand and experience dementia: 1. *Wairua (spiritual experiences)*, 2. *Māori ways of healing*, 3. *Whanau experiences* and 4. *Functioning in the Māori world*.

Conclusions: We identified aspects of dementia that are central to how Māori understand and experience this condition. These findings provide a knowledge base for policy makers and service providers to tailor a dementia pathway that is relevant, appropriate and effective for Māori.





PARALLEL SESSION ABSTRACTS

Diverse populations - inclusion and equality

Date: Friday, 27 July 2018

8-006

FROM EVIDENCE TO PRACTICE: TRANSLATING AN EVIDENCE-BASED INTERVENTION FOR SPANISH-SPEAKING LATINO FAMILIES LIVING WITH/CARING FOR/SUPPORTING A PERSON WHO HAS DEMENTIA

Roberto E Velasquez^{*1}; Martha Rañón^{*1} and Dolores Gallagher-Thompson², (1)Southern Caregiver Resource Center, San Diego, CA, (2)Stanford Alzheimer's Disease Research Center, Stanford University School of Medicine, Palo Alto, CA

Abstract:

The Global action plan on the public health response to dementia is grounded in seven cross-cutting principles, including evidence-based practice for dementia risk reduction and care.

The plan asserts that, based on scientific evidence and/or best practice, it is important to develop strategies and interventions for dementia risk reduction and care that are person-centered, cost-effective, sustainable and affordable, and take public health principles and cultural aspects into account.

Southern Caregiver Resource Center (SCRC) has been implementing evidence-based interventions with Spanish-speaking individuals living with/caring for/supporting a person who has dementia in South San Diego County, USA for the past nine years. This region is home to the largest population of Latino families in San Diego County, including Latinos over the age of 65. The target service area is unique in that it is close to the USA and Tijuana, B.C. Mexico border, most program participants are monolingual Spanish-speaking, are of low socio-economic status, have low literacy levels (including low health literacy), and actively engage in cross-border activities for family and social support, health care, shelter and consumer needs. The primary focus of our work has been to engage in "translational research" by adapting the REACH I and REACH II interventions (Resources for Enhancing Alzheimer's Caregiver Health) into a format that could be feasibly delivered to this unique population. The psycho-educational series are designed to reduce levels of depression and burden and improve the coping skills and overall health of Latino families living with/caring for/supporting a person who has Alzheimer's disease or dementia.

We will share our experience moving from "evidence to practice" with our target population, highlighting key components for successfully adapting the evidence based REACH intervention from a research setting into a structure that is feasible to deliver in a community based, social service setting while taking every effort to preserve the fidelity of the research, and we will share "best practice" approaches for outreach (e.g. working with Promotoras) and engaging key community partners within the target communities.





PARALLEL SESSION ABSTRACTS

Diverse populations - inclusion and equality

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PARALLEL SESSION ABSTRACTS

Inappropriate medication and registries

Date: Friday, 27 July 2018

9-001

MORTALITY ASSOCIATED WITH POTENTIALLY INAPPROPRIATE MEDICATION USE IN FRAIL AND NON-FRAIL COGNITIVELY IMPAIRED OLDER ADULTS

Bryony Porter^{*}; George Savva and Antony Arthur, School of Health Sciences, University of East Anglia, Norwich, United Kingdom

Abstract:

Objectives: Limited research has investigated the outcomes of potentially inappropriate medication (PIM) use in people with dementia or severe cognitive impairment and few studies have examined the role of frailty as a moderator of these outcomes.

This study estimated survival associated with the use of four types of PIM (antipsychotics, anticholinergics, antidepressants and proton pump inhibitors) in frail and non-frail older adults with cognitive impairment.

Methods: The data used were collected as part of the second Cognitive Function and Ageing Study (CFAS II). CFAS II collected data from 7,796 participants and is a nationally representative cohort study of ageing in England. Participants were all aged over 65, were assessed for dementia and asked health and lifestyle questions, including current medications.

Survival was estimated in cognitively impaired individuals from study entry (2008-2011) until 31st October 2016 in users and non-users of PIMs. Cox regression models estimated hazard ratios for each medication, adjusting for multiple covariates, including frailty. The moderating effect of frailty on the link between PIM use and mortality was estimated.

Results: 1,154 cognitively impaired individuals were included in the analysis. Of these 44% were taking at least one potentially inappropriate medication. With the exception of antipsychotic medications (fully adjusted HR 3.15, 95% CI 1.79-5.55), use of potentially inappropriate medications was not associated with worse survival. However, exploratory post-hoc analyses indicated that an increase in the number of medications was associated with significantly worse survival (HR 1.06, 95% CI 1.03-1.10). Being frail was associated with worse survival (HR 1.63, 95% CI 1.13-2.34). Frailty was not found to moderate the relationship between potentially inappropriate medication use and survival.

Conclusions: Use of antipsychotic medications in people with severe cognitive impairment or dementia should be used with caution and only where other treatments have failed. Frail people with cognitive impairment were no more susceptible to PIM than non-frail. However, our results suggest that it is the number of medications used rather than individual PIM that may be more important in the management of health care for people with severe cognitive impairment or dementia.





PARALLEL SESSION ABSTRACTS

Inappropriate medication and registries

Date: Friday, 27 July 2018

9-002

EVIDENCE-BASED CLINICAL PRACTICE GUIDELINE FOR DEPRESCRIBING CHOLINESTERASE INHIBITORS AND MEMANTINE IN PEOPLE WITH DEMENTIA

Emily Reeve*, NHMRC Cognitive Decline Partnership Centre, University of Sydney, Sydney, Australia and The Guideline Development Team, NHMRC Cognitive Decline Partnership Centre, University of Sydney, Australia

Abstract:

Objective: People living with dementia often take multiple medications to treat the symptoms of dementia and their other co-morbidities. Approximately 50% of people with dementia take five or more regular medications, so called polypharmacy, which is associated with increased risk of adverse drug reactions, hospitalizations and mortality. Ensuring optimal medication use in people with dementia involves both prescribing medications that will help achieve care goals and deprescribing (supervised withdrawal) of medications for which risk outweighs benefit. A lack of drug-specific deprescribing guidelines has been reported by health care professionals as a significant barrier to optimizing medication use.

There are currently two classes of medications available to treat the symptoms of dementia: cholinesterase inhibitors (ChEIs) and memantine. The potential benefits and risks of these medications may change over time. The purpose of this project was to develop a guideline to assist healthcare professionals to determine when it might be suitable to trial withdrawal of these medications.

Method: The Guideline Development Team (GDT) consisted of ten people who were one or more of the following: content experts, end-users, or methodology experts. We sought to include healthcare professionals who are involved in the prescription and/or monitoring/management of prescriptions of cholinesterase inhibitors and/or memantine (end-users). Two consumer representatives were also involved as GDT members. We followed the process of developing class-specific deprescribing guidelines, which are based on a comprehensive checklist for successful guideline development and the AGREE-II criteria. We also incorporated requirements for Australian National Health and Medical Research Council (NHMRC) external guideline approval. The process involved a systematic review and used the GRADE (Grading of Recommendations Assessment, Development and Evaluation) process to assess the quality of the evidence and convert the evidence into recommendations. Prior to publication the guideline underwent external review by clinical experts, stakeholders and methodology experts.

Result: Four recommendations and three practice points were developed to guide deprescribing of ChEIs and memantine. The recommendations take into account the quality of the evidence, the risks and benefits of deprescribing, the risks and benefits of continuation, consumer values and preferences, and economic considerations. The guideline also provides guidance on how to conduct deprescribing of these medications (i.e. whether tapering is necessary and what monitoring should be conducted). The guideline recommendations have been approved by the NHMRC and are published with supporting material at <http://sydney.edu.au/medicine/cdpc/resources/deprescribing-guidelines.php>.

Conclusion: While there were limitations to the available evidence, the GDT was able to provide recommendations to guide deprescribing of ChEIs and memantine with the aim of improving quality of life in people with dementia. The recommendations should be considered in the context of the individual and deprescribing should be conducted as a process with consumer engagement throughout. Future work involves development of a consumer version of the guideline and implementation in Australia.



PARALLEL SESSION ABSTRACTS

Inappropriate medication and registries

Date: Friday, 27 July 2018

9-003

HOW CAN RESEARCHERS AND CONSUMERS WORK TOGETHER TO ACHIEVE POSITIVE OUTCOMES THROUGH A RESEARCH PROGRAM TO OPTIMIZE MEDICATION USE IN PEOPLE WITH DEMENTIA?

Lyntara S Quirke^{*}; Emily Reeve and Sarah N Hilmer, NHMRC Cognitive Decline Partnership Centre, University of Sydney, Sydney, Australia

Abstract:

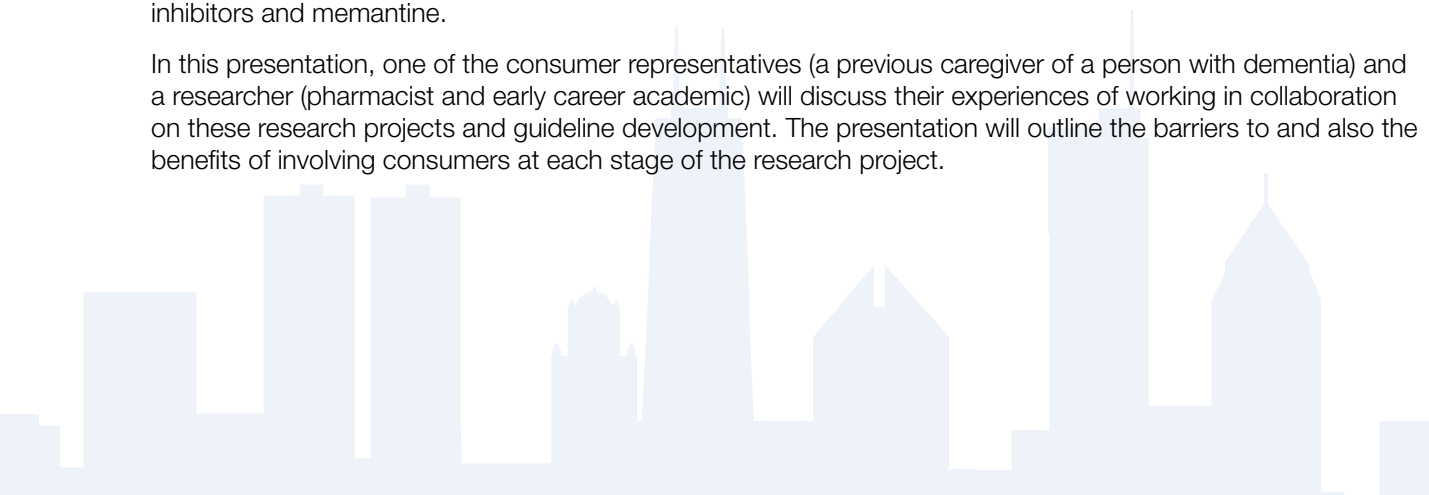
In 2013, the National Health and Medical Research Council (NHMRC) in Australia established a partnership centre for dealing with cognitive and related functional decline in older people. The mission of the Cognitive Decline Partnership Centre (CDPC) is to improve the lives of people with dementia by developing, communicating, and implementing research that improves care. A key pillar of the CDPC is consumer involvement in ALL stages of research. One of the streams of the CDPC, which was prioritized highly by consumers when designing the workplan for the partnership centre, is focused on improving medication management in people with dementia.

Older adults with dementia commonly have multiple chronic conditions that prompt clinicians to prescribe medications. While dementia is a life-limiting disease, progression from mild cognitive impairment to end stage dementia is a process that can occur over many years and may not take a predetermined course. Therefore, aligning pharmacological treatment with changing goals of care can be challenging. Optimizing medications for older people with dementia involves consideration of medical, functional and social issues and goals of care. It involves both prescribing medications that help achieve these goals and deprescribing (withdrawing) medications for which risk may outweigh benefit.

Compared to people without dementia, those with dementia take on average one more medication, even after adjustment for age, gender and co-morbidities. Additionally, approximately 50% of people with dementia take at least one inappropriate medication (that is, a medication where the harm outweighs the benefit in the individual, or when a safer alternative exists).

Over the past four years, the research team has been working in collaboration with consumer representatives on a variety of research projects as well as guideline development. The research projects have spanned from qualitative research and questionnaire development to capture how older adults, people with dementia and their care partners feel about medications and deprescribing to designing an intervention to optimize medication use in people with dementia. Additionally, a consumer representative was involved as a Guideline Development Team member in the development of an evidence-based clinical practice guideline for deprescribing cholinesterase inhibitors and memantine.

In this presentation, one of the consumer representatives (a previous caregiver of a person with dementia) and a researcher (pharmacist and early career academic) will discuss their experiences of working in collaboration on these research projects and guideline development. The presentation will outline the barriers to and also the benefits of involving consumers at each stage of the research project.





PARALLEL SESSION ABSTRACTS

Inappropriate medication and registries

Date: Friday, 27 July 2018

9-004

GLOBALIZING AN APPROACH TO GENERATING NEW KNOWLEDGE AND DRIVING IMPROVEMENTS IN CARE THROUGH INCREASING AWARENESS AND ENGAGEMENT IN DEMENTIA RESEARCH

Piers M Kotting^{*}, Medical School, University of Exeter, Exeter, United Kingdom; Adam Smith, Institute of Neurology, University College London, London, United Kingdom; Yun-Hee Jeon, Sydney Nursing School, University of Sydney, Sydney, NSW, Australia and Martin N Rossor, University College London, London, United Kingdom

Abstract:

In 2012 the UK Prime Minister launched the '*Challenge on Dementia*' to stimulate policy and system change to deliver "major improvements in dementia care and research." The *Challenge* noted "people with dementia and their carers are not routinely offered the opportunity to participate in high-quality research". The National Institute for Health Research (NIHR) National Director for Dementia Research was tasked with delivering the necessary policy and system change to create a nationally consistent system to enable them to do so, should they wish.

A new national public engagement and research recruitment service, Join Dementia Research, was launched in the UK in February 2015. The service enables people to register their interest in research, and uses their data to match them to appropriate studies and allows researchers to contact them. The service is a collaboration between the major dementia charities in the UK (Alzheimer's Society, Alzheimer's Research UK and Alzheimer Scotland) the Department of Health and the National Health Service (NHS).

In the three years since launch, more than 32,000 people have registered with the service, which is used by 187 NHS, University and commercial research organisations to recruit people to studies. 866 researchers have been trained to use the service, which has recruited to more than 150 studies. It has had a direct and indirect impact on research activity with over 30,000 people recruited to dementia studies each year since the service launched, up from 13,000 a year in the preceding 4 years. Of annual survey respondents, 81% say it has increased their awareness of research and 73% that it has made it easier to get into a study.

The work done to access the state of dementia research globally following the G8 Dementia Summit in 2014 and subsequently in establishing the WHO Global Dementia Observatory suggests that research is not routinely offered to people with dementia as part of normal clinical practice. The success of Join Dementia Research in the UK presents an opportunity to develop and adapt the approach for use in other countries to increase public awareness and engagement in research, improve the speed and efficiency of the delivery of research studies and drive improvements in dementia care, treatment and prevention.

The team that established the UK service is working in partnership with Alzheimer's Disease International to share their knowledge and passion for increasing engagement and participation in dementia research by collaborating with stakeholders in other countries to create similar services tailored to local needs. This presentation will describe how the new service was created in the UK, present data on how the service has developed, and the impact it has had on people registering and research recruitment in the UK. It will describe the approach being taken to develop a global network of engagement and recruitment services, presenting as a case study a collaboration with the University of Sydney that was initiated at ADI2017 in Kyoto, to create a new service in Australia.

Key learning objectives for those attending will be to understand the approach taken in the UK and its impact so far, to be able to assess the appropriateness of this approach in other countries, to understand the potential benefits of the approach and how a case might be made for doing something similar in other countries, and to develop contacts with the UK team to be able to explore future potential collaborations.



Inappropriate medication and registries

Date: Friday, 27 July 2018

9-005

DUTCH ONLINE REGISTRY FOR RECRUITMENT OF PARTICIPANTS FOR DEMENTIA STUDIES: HERSENDERZOEK.NL AND BRAIN HEALTH REGISTRY

Marissa D. Zwan¹;Derek Flenniken²;Shannon Finley²;Aaron Ulbricht²;Rachel Nosheny²;Wiesje M. van der Flier³;Sietske A.M. Sikkes³;Philip Scheltens³;Diana Truran-Sacrey²;Michael Weiner²;Niels D. Prins³ and **Marco M. Blom**⁴, (1)Alzheimer Center, Alzheimer Center, Dept Neurology, VU University Medical Center, Amsterdam Neuroscience, Amsterdam, Netherlands, (2)Center for Imaging of Neurodegenerative Diseases, San Francisco Veterans Administration Medical Center, San Francisco, CA, (3)Alzheimer Center, Dept Neurology, VU University Medical Center, Amsterdam Neuroscience, Amsterdam, Netherlands, (4)Dutch Alzheimer's society, Amersfoort, Netherlands

Abstract:

Objective: Difficulty in participant recruitment is a significant barrier to clinical dementia studies. In collaboration with Brain Health Registry (BHR), the Dutch online registry Hersenonderzoek.nl was set up for online recruitment of participants in the Netherlands. Here we present preliminary results with respect to participant registration and enrollment in four specific studies.

Method: Hersenonderzoek.nl consists of a dedicated website connected to an IT platform that allows data access and modification. This platform was provided as a Software as a Service solution by BHR and adjusted according to Dutch culture and language. Subjects interested in participating in brain research were reached via our dedicated Facebook recruitment campaign targeted to (non-demented) individuals aged 50-70 years. The online registration process consists of a 5-minute minimal dataset (MDS) questionnaire including demographics, subjective complaints and medical history. As a pilot, eligible subjects for four specific studies were prescreened based on the MDS and invited to participate. Interested participants were contacted by the study investigator for further evaluation for possible enrollment.

Result: Since September 21st 2017, n=7805 participants have registered at Hersenonderzoek.nl. Table 1 provides an overview of registrants characteristics. Four studies have (complementary) recruited participants via our platform; ABIDE-Delphi, EuroSCD (both online observational studies), CatchCog (onsite observational study) and Generation 1 (onsite intervention study). Prescreening identified 204 potential eligible participants. After further evaluation by the study investigator, 102 participants have successfully been enrolled in studies, resulting in a conversion rate of 0.50 (Table 2). Recruitment is currently ongoing for five other studies.

Conclusion: Hersenonderzoek.nl is a growing cohort of subjects interested in participating in brain studies. Our preliminary findings demonstrate the feasibility to recruit study participants via Hersenonderzoek.nl for a variety of brain research studies with a high conversion rate. Following BHR, the launch of Hersenonderzoek.nl provides proof of concept for a scalable international online platform for participant recruitment. Next steps for Hersenonderzoek.nl are 1) to increase the number of registrants; and 2) increase the number of recruiting studies via the platform, including European Prevention of Alzheimer's Dementia (EPAD).

Table 1. Demographics of Hersenonderzoek.nl cohort

Total	7805
Age	58.5±11.4
Female	5087 (77%)
Education (Verhage)	4.7±1.0
Employed	3980 (51%)
Retired	2297 (29%)
Subjective memory complaints	2088 (27%)
Diagnosis MCI or dementia	178 (2%)
MCI or dementia in 1 st degree family	2402 (31%)
(History of) cardiovascular disease	780 (10%)
(History of) neurological disease	321 (4%)
(History of) psychiatric diseases	1485 (19%)

Data are presented as mean ± SD or n (%). MCI, Mild cognitive impairment.

Table 2. Prescreening of participants for studies

Study	Population	Prescreened (n)	Enrolled (n)	Conversion
ABIDE-Delphi	Caregivers	139	54	0.39
EuroSCD	Subjective memory complaints	50	43	0.86
CatchCog	Mild cognitive impairment	9	2	0.22
Generation 1	APOE ε4 carriers	6	3	0.50
Total / mean		204	102	0.50



PARALLEL SESSION ABSTRACTS

Inappropriate medication and registries

Date: Friday, 27 July 2018

9-006

USE OF POTENTIALLY INAPPROPRIATE MEDICATIONS IN PEOPLE WITH DEMENTIA IN VIETNAM AND ITS ASSOCIATED FACTORS

Tuan Anh Nguyen*, Quality Use of Medicines and Pharmacy Research Centre, School of Pharmacy and Medical Sciences, University of South Australia, Adelaide, Australia

Abstract:

Objective: This study aimed to examine the use of potentially inappropriate medicines that may affect cognition (PIMcog) in people with dementia and its associated factors.

Method: Medical records of all out-patients with dementia attending a tertiary hospital in Vietnam between 1st, Jan 2015 and 31st, Dec 2016 were examined. Medicine use was assessed against a list of previously published PIMcog. Variables associated with having a PIMcog were assessed using a multiple logistic regression. Concomitant use of cholinesterase inhibitors (CEIs) and anticholinergics, and antipsychotics use was also examined.

Result: Of the 128 patients, 41% used a PIMcog, 39.1% used CEIs concomitantly with anticholinergics, and 18% used antipsychotics of whom a quarter used antipsychotics longer than three months. The initial doses of risperidone were not optimal in treatment of behavioural and psychological symptoms of dementia. Number of hospital visits (adjusted OR 1.08; 95% CI 1.02 – 1.16) and number of treating specialists (adjusted OR 0.61; 95% CI 0.45 – 0.83) were found to be associated with PIMcog use.

Conclusion: This study highlights a high level use of medicines that can further impair cognition or reduce the effectiveness of CEIs in people with dementia. Dementia is an emerging area of disease burden in Vietnam and efforts to improve quality use of medicines for this population are warranted, particularly supporting awareness of and reduction of use of medicines that further impair cognition.





POSTER ABSTRACTS

Awareness and stigma - Poster

P01-001

PUBLIC STIGMA TOWARDS A PERSON WITH ALZHEIMER'S DISEASE: EXAMINING EXPLICIT AND IMPLICIT MEASURES

Perla Werner* and Lilcah Raviv-Turgeman Ms., Community Mental Health, University of Haifa, Haifa, Israel

Abstract:

Objective: Driven by abundant anecdotal evidence regarding high levels of public stigma towards persons with Alzheimer's disease (AD), research in the area is increasing rapidly. However, most quantitative studies until today showed relatively low levels of stigma being attributed to a person with AD. One of the potential explanations for these low levels of stigma might be the fact that, all the studies in the area have assessed stigma using explicit attitudes. The aim of this study was to compare explicit and implicit stigmatic attitudes towards a person with AD.

Method: The stigmatic beliefs of 375 college students (mean age = 25.5; 58.9% female; 64.3% Jewish) were examined using explicit and implicit measures. Explicit attitudes were assessed using a modified version of the Attribution Questionnaire. Implicit attitudes were assessed using a Single Target Implicit Association Test.

Result: Participants scored significantly higher in the implicit stigma measures, when compared to the explicit stigma measures, across all stigma domains.

Conclusion: Focusing exclusively on explicit stigma may provide an incomplete perspective, be subject to social desirability biases, and underestimate the extent of stigma towards a person with AD. The utility of both implicit and explicit measures for understanding AD stigma should be considered.





POSTER ABSTRACTS

Awareness and stigma - Poster

P01-003

A PROTOCOL FOR A RANDOMIZED CONTROLLED TRIAL TO REDUCE DEMENTIA-RELATED STIGMA IN THE GENERAL PUBLIC

Sarang Kim^{*1}; Perla Werner²; Alice Richardson¹ and Kaarin J Anstey³, (1)Research School of Population Health, Australian National University, Canberra, Australia, (2)Department of Community Mental Health, University of Haifa, Haifa, Israel, (3)Neuroscience Research Australia, University of New South Wales, Sydney, Australia

Abstract:

Objective: Dementia is a highly stigmatized condition leading to significant negative effects on the health and well-being of people with dementia, and their carers. Stigma can also prevent people from seeking help. This results in people missing out on timely diagnosis and the utilization of health and social services. It is therefore vital to develop programs to reduce the stigma of dementia. Despite the success of interventions for reducing the stigma of mental illnesses, research investigating strategies to tackle dementia-related stigma is lacking. This project therefore aims to develop and evaluate an intervention program (Dementia Stigma Reduction (DESeRvE)) aimed at the general public to reduce dementia-related stigma.

Method: DESeRvE is an online 2x2 factorial randomized controlled trial (RCT). The project aims to recruit 500 Australian adults aged 40 and older who have internet access. The DESeRvE project involves four conditions (education (ED), contact (CT), education + contact (ED+CT), and control) to evaluate the stigma reduction intervention for dementia. The ED group will complete an adapted module from the Body Brain Life (BBL), an online intervention program designed to reduce the risk of developing dementia. It provides in-depth information about dementia in terms of definition, symptoms, pathology, and treatments. The CT group will have access to simulated contact with PWD and carers. The DESeRvE program will be designed so that the participant in the CT condition can type in questions online about what they would want to learn from people with dementia or carers. The program will then search for pre-recorded video clips using search terms/keywords and play relevant video clips in response to questions. The ED+CT group will receive materials from both CT and ED groups. The Control group will not receive any intervention programs.

Result: The primary outcome for the intervention is dementia-related stigma measured with a modified Attribution Questionnaire (AQ). The secondary outcome is knowledge of dementia measured by the Dementia Knowledge Assessment Scale (DKAS). The level of stigma and knowledge measured in AQ and DKAS between the experimental and control groups immediately after the intervention, as well as 12 weeks post-intervention, will be measured and compared against the level of stigma prior to the intervention. The efficacy of the intervention will also be assessed between age groups to investigate whether different approaches work differently across age groups.

Conclusion: DESeRvE can be a valuable tool to reduce dementia-related stigma. If proven effective, it will encourage the general public to enable people living with dementia to feel more included and enhance their quality of life. By reducing stigma through an effective stigma reduction intervention, it is also envisaged that people will be more likely to visit GPs or other health professionals as soon as early symptoms of dementia are noticed.



POSTER ABSTRACTS

Awareness and stigma - Poster

P01-004

SUBJECTIVE MEMORY CONCERNS AND FAMILY HISTORY ARE MAJOR PREDICTORS OF DEMENTIA WORRY

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Abstract:

Objectives: Dementia worry is conceptualized as a type of health anxiety, where people experience negative emotions (e.g. fear and anxiety) and cognitions (e.g. rumination) related to the perception that the onset of dementia is imminent (Kessler et al., 2012). People with high levels of dementia worry interpret benign cognitive changes as indicative of disease, despite evidence to the contrary. Of major concern is that dementia worry may impact access to care and support and cause undue emotional distress, impacting quality of life. Factors associated with dementia worry include a family history of dementia, subjective cognitive complaints, being middle aged, being female, and having less knowledge about dementia, although the research findings are inconsistent. One of the major limitations of previous research is the reliance on single item measures of both dementia worry and other factors, such as dementia knowledge, and the use of small samples. This study adopted a more psychometrically rigorous approach to examining this phenomenon in a large sample of adults (n=3377).

Methods: Factors thought to be associated with dementia worry were identified from the literature. The following scales were presented to participants (mean age = 51, 91% female) enrolled in the 2016 Preventing Dementia MOOC (Massive Open Online Course): the Depression, Anxiety and Stress scale-21 item (Lovibond & Lovibond, 1995); the Dementia Knowledge Assessment Scale (Annear et al., 2015) and the Dementia Worry Scale (maximum score of 60; Suhr & Isgrigg, 2011). Surveys were completed online prior to commencement of the course.

Results: Regression analysis supported a five factor model which explained 24% of the variance in dementia worry $F(17, 3305) = 63.1, p < .001, R^2 = .24$. Subjective assessment of memory performance two years prior was a significant predictor ($F(2, 3305) = 49.6, p < .001$), with declining memory predicting higher dementia worry scores ($B = 3.6$) than improving memory ($B = -.27$). Subjective assessment of current memory performance was also significant ($F(4, 3305) = 43.5, p < .001$), with those rating their memory as "Poor" ($B = 25.0$) experiencing higher dementia worry than participants who rated their memory as "Excellent" ($B = 14.6$). Positive family history ($F(1, 3305) = 39.3, p < .001$) had a moderate impact on dementia worry ($B = 1.5$). Adjusting for depression, anxiety and stress, dementia knowledge ($B = -0.07, p < .001$) and age ($B = 0.03, p < .001$) also had small but significant effects on dementia worry.

Conclusion: Using a psychometrically rigorous approach in a large sample, the current study identified a number of significant predictors of dementia worry. Consistent with the limited research in this area, subjective appraisal of memory function (past and present) and family history are associated with higher levels of dementia worry, and these factors appear more influential than having more dementia knowledge or being older. It may be possible to attenuate dementia worry by helping people appraise their memory appropriately. It is conceivable, given the worldwide increase in dementia incidence, that dementia worry will also become more prevalent. Therefore, understanding the factors related to dementia worry will be important to effectively manage its associated psychological impact, as well as the potential effect it might have on access and provision of health care.

POSTER ABSTRACTS

Awareness and stigma - Poster

P01-005

LIVING AND LEARNING WITH DEMENTIA

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Abstract:

Since 2015, SDWG members have been involved in iPad training sessions which have had a huge impact: from enabling independent living to allowing members to have their voices heard online, these new skills have enhanced the lives of people with dementia. In early 2017, three members embarked on a partnership project with Untold Motion Picture Company: a film aimed at sharing this impact and highlighting the key message that a dementia diagnosis does not stop a person from learning. Henry Rankin, Pat McGonigal and Geordie Woods were true partners in the filmmaking process, not only starring in the film but also learning new skills in filmmaking and editing as they worked with the Untold Motion Picture Company to put together



a final product which showcased the importance of learning for people with dementia. The film is titled "Living & Learning with Dementia" and was premiered in a special event over the summer of 2017. It has since gone on to be used as a training tool for the dementia workforce, with viewers feeding back that it has "changed [their] perspective", and as an empowering piece of media for people with dementia who have commented that it has "given them hope". Henry Rankin says his involvement was "one of the best things that I've done", commenting that "we learned so much which brought us closer together. I hope the film helps other people with dementia and shows that it doesn't stop you from learning new things".





Awareness and stigma - Poster

P01-006

WHAT DO THE GENERAL PUBLIC REALLY WANT TO KNOW ABOUT DEMENTIA?: A FOCUS GROUP STUDY

Sarang Kim^{*1}; Perla Werner²; Alice Richardson¹ and Kaarin J Anstey³, (1)Research School of Population Health, Australian National University, Canberra, Australia, (2)Department of Community Mental Health, University of Haifa, Haifa, Israel, (3)Neuroscience Research Australia, University of New South Wales, Sydney, Australia

Abstract:

Objective: Dementia is a highly stigmatized condition. The two main stigma reduction strategies that have been successfully applied to other stigmatized conditions such as mental illness are education and contact. These strategies enhance awareness and understanding of stigmatized conditions. There has been research exploring people's knowledge and attitudes towards dementia and people with dementia. However, what people do not know and therefore would like to learn about dementia has not been explored.

Method: Focus groups were conducted with 1) the general public on what they would like to learn from people with dementia; and 2) consumers (people with dementia and carers) on what they would like the general public to know about them and about living with dementia. Thirty one people (3 males and 28 females) aged between 47 and 82 (M=63.7, SD=10.2) participated in six focus groups. They were recruited through local community newspapers. The audio files from the focus groups were transcribed verbatim and transcripts were coded to determine themes using qualitative content analysis.

Result: The majority of participants knew/have known someone with dementia and showed some level of understanding on dementia although some lacked basic understanding on dementia making statements such as 'dementia is different from Alzheimer's disease'. Participants' responses could be classified into three distinctive themes: medical, insights, and practical/management. Medical theme included 'difference between normal aging and dementia', 'causes of dementia' and 'how dementia is diagnosed'. Statements such as 'what people with dementia want/need' and 'whether people with dementia know that they have dementia' sought insights from people living with dementia. Practical or management theme included 'strategies that can assist in caring for someone with dementia', 'how family members and carers better support themselves' and 'how to behave around people with dementia'.

Conclusion: The findings from the focus groups suggest that the general public want to know not only the medical aspects of dementia, but also the ways/ strategies to better manage the situation and to help/support people with dementia. They are also keen on learning about what it is like living with dementia. Resources addressing these questions should therefore be available to the general public. The information gathered from these focus groups will be used to develop an online intervention program to reduce dementia-related stigma via having virtual contact with people with dementia and carers.





POSTER ABSTRACTS

Awareness and stigma - Poster

P01-007

ADVOCATING FOR ALZHEIMER'S RESEARCH IN NEW ZEALAND: A UNIQUE PERSPECTIVE

Edward John Betts^{*}, Advocate, Independent, New Plymouth, New Zealand

Abstract:

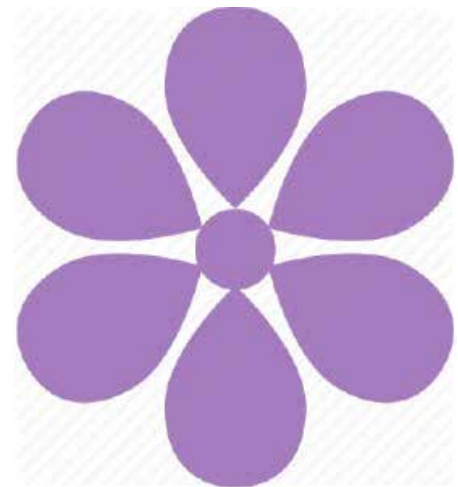
In spite of the rapidly increasing number of people being diagnosed with Alzheimer's in New Zealand, there is a very small amount of funding allocated for Alzheimer's research, there is no hard data on prevalence or mortality and the stigma of Alzheimer's legitimates political and bureaucratic indifference and inertia.

This Project initially directed towards increased funding for brain research now is also directed at finding better data and bringing Alzheimer's information to the public. The writer sees these two activities as prerequisites.

The writer will describe his activities in raising funds for Alzheimer's research, bringing Alzheimer's into the public arena and in seeking hard data, especially the relevance of correctly completed death certificates.

These themes will be presented in narrative form based on direct experience and accompanied, if permitted with projected notes and videos.

The writer has experienced Alzheimer's as a carer, diagnosis to death for eight years and as an Independent Advocate for two years





POSTER ABSTRACTS

Awareness and stigma - Poster

P01-008

AWARENESS AND STIGMA OF DEMENTIA IN THE PHILIPPINES: THE VIEWS OF STUDENT NURSES

Joanne Mary Brooke Dr*, OxIMNAHR, Oxford Brookes University, Oxford, United Kingdom and Maria Theresa Belciña Dr, College of Nursing, Silliman University, 1 Hibbard Ave, Dumaguete, Philippines

Abstract:

Objectives: The population of the Philippines in 2015 was projected to be 101,803,000, although this population has traditionally been considered a young population, this is being to change. The estimated number of people living with dementia in the Philippines in 2015 was 301,000, which is predicted to increase to 1,149,000 by 2050 (Alzheimer's disease International, 2014). The objective of this study was to explore student nurses perceptions, understanding and beliefs at the beginning and towards the end of their nursing programme.

Methods: A qualitative exploration of 2nd and 4th year student nurses nurse's perceptions, understanding and beliefs of dementia studying in a Higher Education Institution in a city in the Philippines. Focus groups were chosen to develop an understanding of student nurse's views at the beginning and towards the end of their nursing programme. A question route was developed with key questions and prompts, all students provided informed consent. Focus groups provided the students with a shared culture, and natural setting, where they were able to influence each other and be influenced by each other, as they would in the classroom and clinical placement. Each focus group was audio-recorded and transcribed verbatim; data was analysed using thematic analysis as described by Braun and Clarke (2006).

Results: Focus groups (n=6), were completed during March 2017, with second (n=26) and fourth year (n=27) student nurses. Focus groups lasted between 28.31 to 50.06 minutes, with a mean average of 42.29 minutes. Two broad themes were identified from the analysis; firstly, students on entering their programme had a general lack of awareness of dementia and discussed their beliefs that 'dementia and memory loss was a natural part of aging' and not seen as a lift threatening medical condition, although simultaneously considered dementia to be rare in the Philippines. Secondly, all students had developed an understanding of dementia as a disease, but discussed the 'impact of diagnosis', which included both a concern of the stigma attached to a diagnosis, and uncertainty on how a diagnosis would support the family and the person with dementia.

Conclusion: Student nurses both at the beginning and towards the end of their programme discussed how their knowledge and awareness of dementia had improved, although they still reported limited experience of caring for a person with dementia. The family orientated culture of the Philippines and the importance of caring for their older family members at home was acknowledged, which led the students to discuss the need for awareness and educational campaigns to raise the profile and basic understanding of dementia. This was also felt important to remove the stigma for the family members when an older relative did receive a diagnosis of dementia. Mental health issues were considered not be taken seriously, which was reflected in the lack of services to diagnose and provide support and guidance to a person with dementia and their family members. One student summed it up as: dementia is life threatening, but is it not seen like that; it is common, but not commonly known.

References:

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Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77–101.



POSTER ABSTRACTS

Awareness and stigma - Poster

P01-009

ATTITUDES AND KNOWLEDGE OF DEMENTIA IN PAKISTAN: PERCEPTIONS OF THE GENERAL PUBLIC

Nicolas Farina¹; Sara Balouch¹; Rosalind Willis² and Asghar Zaidi², (1)Brighton and Sussex Medical School, Brighton, United Kingdom, (2)University of Southampton, Southampton, United Kingdom

Abstract:

Over the coming decades, the prevalence of dementia is expected to rise due to an aging population, and this public health challenge will be particularly challenging in lower and middle-income countries. Pakistan is a typical exemplar which to date has had very little research and policy making to address the challenge of dementia.

This presentation reports on a part of a larger project funded by Age International, conducted in Pakistan about understandings of dementia among people who have a mild diagnosis of dementia, their family carers, the general population, and key stakeholders of the society.

Utilising specially designed vignettes of dementia patients, this presentation will analyse public attitudes and knowledge of dementia. A series of Focus Group Discussions were completed during 2017 with the public in two metropolitan centres in Pakistan (Lahore and Karachi) (n=40). An induction led thematic analysis was completed. It was identified that many participants had little awareness and knowledge about dementia, which led to incorrect and often harmful perceptions of cause and prognosis of dementia. The responsibility of care was often seen to rest with the family, which can in part be attributed to religious teachings and societal norms, but also lack of formal services. Importantly, participants were able to identify that greater awareness was needed, though this should be accompanied with improved healthcare facilities at the primary care level. This presentation will further highlight the themes identified from the research undertaken in the project and discuss the potential implications for future dementia awareness strategy.



POSTER ABSTRACTS

Awareness and stigma - Poster

P01-010

OBJECTS OF AWARENESS IN ALZHEIMER'S DISEASE: PATTERNS OF CHANGE ACCORDING TO DEMENTIA SEVERITY

Marcia C.N. Dourado^{*1}; Isabel Barbeito Lacerda¹; Raquel Luiza Santos¹ and José Pedro Simões Neto², (1) Center for Alzheimer's disease, Federal University of Rio de Janeiro - Institute of Psychiatry, Rio de Janeiro, Brazil, (2) Sociology and Political Science Department, Federal University of Santa Catarina, Florianópolis, Brazil

Abstract:

Objective: Lack of awareness of deficits is a clinically relevant feature of dementia that affects the maintenance of decision capacities, the management and safety of people with Alzheimer's disease (PwAD) and increases the caregiver burden. This study aims at comparing the different objects of awareness of deficit and the factors associated to each of them in mild and moderate Alzheimer Disease (AD).

Method: Using a cross-sectional design, 128 mild and moderate PwAD were assessed. Awareness was evaluated by scoring discrepant responses between PwAD and their caregivers across domains including cognitive functioning and health condition, functional activity impairments, emotional state, social functioning, and interpersonal relationships.

The PwAD completed assessments about quality of life, cognition and their awareness of disease. The caregivers provided information about the PwAD (including demographics, the ability to perform activities daily living (ADL), awareness of disease, functionality, and dementia severity) and received quality of life and burden of care assessments.

Result: Moderate PwAD were more severely cognitive impaired according to the Mini-Mental State Examination ($p < 0.01$). They also scored higher on the neuropsychiatric symptoms ($p < 0.05$) and on the functionality ($p < 0.01$) assessments. Mild PwAD showed a mildly impaired awareness ($n=40$; 54.05%), followed by preserved awareness ($n=17$; 22.97%), moderately impaired ($n=15$; 20.27%), and absent awareness ($n=2$; 2.70%). The moderate group showed higher presence of moderately impaired awareness ($n=22$; 40.74%), followed by mildly impairment ($n=18$; 33.33%), absent awareness ($n=9$; 16.66%), and preserved awareness ($n=5$; 9.25%). The awareness of functional activity impairments domain showed a greater discrepancy compared with the other domains, in both severity of disease groups, followed by awareness of cognitive functioning and health condition domain, awareness of emotional state domain and awareness of social functioning and relationships domain. Interestingly, the findings showed no difference between the mild and moderate groups in awareness of emotional state and of social functioning and relationships. We found that ADL may have an intrinsic relationship with unawareness phenomenon, suggesting that deficits in ADL permeate awareness impairment in mild and moderate groups. For the mild group, impaired ADL was related with unawareness of emotional state, awareness of functional activity impairments and awareness of disease. In the moderate group, ADL was a predictor in three domains: awareness of cognitive functioning and health condition, awareness of functional activity impairments and awareness of disease.

Conclusion: The findings of this study raise questions about the behavior and nature of the phenomenon of awareness. Each domain is related to different factors, according to the severity of the dementia. Clarifying the differences and specificities of awareness is essential to manage this key aspect of dementia, and to assist in therapeutic intervention and quality of life.



POSTER ABSTRACTS

Awareness and stigma - Poster

P01-012

RAISING AWARENESS OF THE ROLE OF PHYSICAL ACTIVITY IN HEALTHY AGEING: ACTIVE AGEING AMBASSADORS

Claire Sexton*, University of California San Francisco, San Francisco, CA; Kristine Yaffe, UCSF, San Francisco and Helen Dawes, Oxford Brookes University, Oxford, United Kingdom

Abstract:

Between 2015 and 2051, the number of people in the UK living with dementia is predicted to rise from 850,000 to over 2 million. Given the current absence of disease-modifying treatments, interventions that could delay the onset of dementia could have a huge impact. For example, it is estimated that delaying the onset of dementia by five years would reduce the number of people living with dementia by a third by 2050, result in half a million fewer informal care-givers, and save the economy £2.1 billion a year.

Observational studies have repeatedly identified physical inactivity as a key modifiable risk factor for dementia, with one review estimating that a 25% reduction in physical inactivity worldwide could potentially prevent nearly 1 million cases of Alzheimer's disease. Furthermore, there is also evidence to suggest that exercise programs can improve upon people living with dementia's ability to perform activities of daily living.

Despite such known health benefits, rates of inactivity remain high amongst older adults. In the UK, 48% of people aged 75-84 years report getting fewer than 30 minutes of activity per week, with this figure rising to 71% of those aged over 85 years.

In order to *inform* greater numbers of people about research into physical activity and to *inspire* people to help make their communities more active, we are developing a scalable ambassador program, which includes a workshop that is suitable to be delivered to community groups of any size.

The workshop is being developed by a multi-disciplinary team of physical activity researchers (with expertise spanning public health, movement science, epidemiology and neuroscience) in partnership with organisations that promote physical activity (e.g. Dementia Adventure) and the local community. As a result, the workshop can be delivered by volunteer ambassadors from any background (research, charity, healthcare, industry, community).

Through activities targeting participants' knowledge, skills and attitudes, by the end of the workshop, participants should be able to:

- Discuss the breadth of benefits physical activity has on health outcomes in aging populations
- Critically appraise research findings reported in the media
- Define moderate- and vigorous-intensity physical activity
- Summarize the physical health guidelines for older adults
- Provide examples of types of activities that are suitable for older adults, and people living with dementia
- Question the influence of cultural and environmental factors on activity levels
- Propose a variety of ways to promote activity within their community

Ultimately, we hope that this program will further the Global Brain Health Institute's aim of creating social change, reducing stigma and inspiring optimism and dignity for elders.



Awareness and stigma - Poster

P01-013

ATTITUDES TOWARDS DEMENTIA IN ADOLESCENTS: THE ASSOCIATION WITH LEVEL OF CONTACT

Nicolas Farina¹; Laura J Hughes¹; Alys Griffiths² and Sahdia Parveen³, (1)Brighton and Sussex Medical School, Brighton, United Kingdom, (2)Leeds Beckett University, Leeds, United Kingdom, (3)Centre for applied dementia studies, University of Bradford, Bradford, United Kingdom

Abstract:

Introduction: Stigma has a profound effect on those living with dementia which can lead to social isolation, reduced quality of life, and loss of independence. It is also a major barrier for seeking and accessing support, diagnosis, treatment, and information. Stigma towards dementia appears to form during childhood, though it is unclear how to best combat the formation of these negative attitudes. In the broader literature, contact with dementia is one route to reduce stigma, though this association has not been explored in adolescents.

Objectives: To explore the adolescents' level of contact with dementia and how it is associated with attitudes towards dementia.

Methods: 901 adolescents (M = 14.9 years old; SD=1.4) were recruited from secondary schools across Sussex, England. Participants were asked to complete a series of questionnaires about their level of contact with dementia (Adolescent Level of Contact of Dementia Questionnaire), alongside their attitudes towards dementia (Allophilia Scale and the Adolescent Attitudes towards Dementia Scale).

Results: Being male ($t = -7.54$, $p < 0.0001$) and older ($r_s = -0.11$, $p = 0.003$) was associated with poorer attitudes toward dementia. Adolescents' previous contact with dementia (both direct and indirect contact) was positively associated with all indices of attitudes towards dementia ($p < 0.01$). These associations remained even after controlling for age and gender.

Conclusions: Contact between adolescents and people with dementia appears to be an effective way of combatting stigma towards the condition. This relationship existed even without factoring in whether the contact was seen positively or negatively. There was no compelling evidence that direct contact was more effective than indirect contact. Future research should explore how to feasibly and effectively reduce stigma towards dementia in schools.





POSTER ABSTRACTS

Awareness and stigma - Poster

P01-014

SOCIAL COGNITION AND AWARENESS IN DEMENTIA

Tatiana Belfort¹; **Marcia C.N. Dourado¹**; José Pedro Simões Neto² and Raquel Luiza Santos¹, (1)Center for Alzheimer's disease, Federal University of Rio de Janeiro - Institute of Psychiatry, Rio de Janeiro, Brazil, (2) Sociology and Political Science Department, Federal University of Santa Catarina, Florianópolis, Brazil

Abstract:

Objective: Social cognition is the capacity to interpret and predict another's behavior according to beliefs, intentions, and emotions, and the ability to decode environmental stimuli in order to be better able to adapt to new

situations. A key question is the relationship between social cognition and awareness of disease in dementia. Awareness of disease is the recognition of changes caused by deficits related to the disease process. The aim of this study was to investigate the relation between social and emotional functioning (SEF) and awareness of disease in Alzheimer's disease (AD). It is hypothesized that impairments in SEF will be independent of unawareness of disease in AD.

Method: Using a cross-sectional design, a consecutive series of 50 people with mild to moderate AD and their 50 family caregivers were assessed. People with AD completed assessments about quality of life, cognition, SEF, and their awareness of the disease. The caregivers provided information about PwAD (including demographics, ability to perform activities of daily living, awareness of disease, functionality, SEF, and dementia severity) and had their quality of life, cognition and burden of care assessed. The study variables were awareness of disease (total score, awareness of cognitive deficits and health condition, awareness of social functioning and relationships, awareness of instrumental and basic activities of daily living, neuropsychiatric symptoms, cognition, working memory, quality of life, functional activities, presence of depressive symptoms, and caregivers burden and cognition.

Result: There was a significant difference between self-rated SEF and informant-rated SEF ($P = .034$). In 56% ($n = 28$) of the cases, self-rated SEF was lower than the informant-rated SEF. People with AD mostly (56%, $n = 28$) had mildly impaired awareness of disease, 20% ($n = 10$) had moderate impaired awareness of disease, and 6% ($n = 3$) were unaware of the disease. A multivariate linear regression examined the association between informant-rated SEF score and the variables. The model included the variables that were significantly correlated (the domain awareness of social functioning and relationships, people with AD functionality, depressive symptoms and caregivers' burden, and informant-rated QoL of people with AD). The social functioning and relationship domain ($P < .01$), informant-rated QoL of people with AD ($P < .05$) were significantly associated with informant-rated SEF.

Conclusion: The relationship between informant-rated SEF and the awareness of social functioning and relationship supports the multidimensional nature of awareness. The relationship between SEF and awareness of social functioning and relationship domain shows that they are comprised of judgments related to perceptions about oneself, values, and beliefs qualitatively different from awareness of memory or functionality, which can be directly observed.



P02-001

A COGNITIVE PROMOTION COURSE FOCUSING ON LIFE FOR DEMENTIA ELDERS IN THE COMMUNITY

Shu-Chun Lee^{*}; Nai-Yu Deng; Jun-Rui Su and Hui-Yau Zhao, Taipei City Hospital, Taipei, Taiwan

Abstract:

Objective: The prevalence of dementia in Taiwan is gradually increasing, and it is estimated that the number of people with dementia will exceed 190,000 in 2011. Due to cognitive decline, people of early diagnosis of mild dementia lacked interest in daily activities and social withdrawal at home. Therefore, given the appropriate cognitive programs, could make people with dementia focusing on their daily life function is particularly important. We provide cognitive interaction courses for groups of 5 to 10 people and try to improve the happiness and quality of life of people with dementia by manipulating various topics.

Method: The cognitive interaction courses were organized by occupational therapists of Wenshan Community Rehabilitation Center from October 20, 2017 to November 22, 2017. Participants had a diagnosis of mild dementia with a CDR score greater than 0.5. Courses are conducted weekly, for a total of eight sessions of 90 minutes each. The topics of the eight courses focus on attention, calculation, orientation, visual discrimination, and problem solving. The eight topics of daily living courses focus on attention, calculation, orientation, visual discrimination, oral expression, and problem solving. At the end of each course, a satisfaction survey is conducted.

Result: A total of 22 elderly people with mild dementia participated in this course. Eleven of them were male, with an average age of 82 years, 90.9% married, 72.8% mild dementia, 63.8% living in the Wenshan District. A total of 82 person times participated in the cognitive interaction courses, with an average of 10 persons per course, and 85.4% of the persons responded very satisfied with the courses.

Conclusion: The courses provide accessibility services for elders with dementia in community. Most participants were satisfied with the cognitive interaction courses and looked forward to follow-up courses. In the future, the service effectiveness may be evaluated to understand the benefits of the courses for the elderly with dementia.

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POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-002

TESTING AN EASY READ VERSION OF THE ADULT SOCIAL CARE OUTCOMES TOOLKIT TO ASSESS QUALITY OF LIFE IN COMMUNITY DWELLING OLDER PEOPLE WITH COGNITIVE IMPAIRMENT

Lyn Phillipson Dr¹; James Caiels Mr²; Towers Ann-Marie Ms² and Susan Jenkins Mrs³, (1)School of Health and Society, Faculty of Social Sciences and Australian Health Services Research Institute, University of Wollongong, Wollongong, NSW, Australia, (2)Personal Social Services Research Unit, University of Kent, Kent, United Kingdom, (3)Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia

Abstract:

Understanding the extent to which social care is promoting choice and quality of life for community dwelling older people is critical in an aging society. Given the rising numbers of older people with dementia, the development of inclusive methods which support valid and reliable outcome assessment is also imperative. Valid tools which promote the views of community dwelling populations are also needed given the increasing emphasis on provision of home based care, and the use of consumer directed care models in the UK, US, Australia, and parts of Europe.

This paper reports on the adaptation and cognitive testing of an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT-ER), originally developed for adults with intellectual disabilities and autism. The survey was used to assess the care-related quality of life of community dwelling older people with cognitive impairment in receipt of a consumer directed Home Care Package in a region of NSW (Australia). Cognitive interviewing was used to explore the appropriateness of pictures, wording and visual scales to assess outcomes in the domains of: control over daily life; accommodation cleanliness and comfort; personal cleanliness and comfort; safety; social participation; occupation and dignity. Following an initial set of interviews (n=16), minor changes were made to some pictures and one set of response options to better suit an older cohort. Re-testing with additional participants (n= 10) confirmed that amendments were useful in improving the suitability of the measure for this population. Interviews with all n=26 participants promoted understanding of the factors influencing areas of greatest need, especially in the domains of: control over daily life, social participation and occupation. The value of using the ASCOT-ER to enable more people with cognitive impairment to give their own views regarding their care-related quality of life and to provide insights to improve the practice of consumer directed home based care are discussed.



POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-003

MEETING THE SEX AND INTIMACY NEEDS OF PEOPLE WITH DEMENTIA IN CARE HOMES: AN ALZHEIMER'S SOCIETY UK INNOVATION SPRINT PROJECT

Colin Capper Mr, Research and Development, Alzheimer's Society UK, London, United Kingdom and **Sally Copley**, Policy, Campaigns and Partnership, Alzheimers Society, London, United Kingdom

Abstract:

We will present findings from an Innovation Sprint project which tackled issues around Sex and intimate relationships for people living with dementia in care homes, a taboo topic which is both under-researched and discussed. During a two month process the Society's innovation team worked with people affected by dementia, academics, policy makers, regulators, care providers, commentators and practitioners from a range of disciplines to understand the practical challenges of meeting the sex and intimacy needs of people living with dementia in care homes and develop a range of solutions to meet these.

Alzheimer's Society's new 5-year strategy "A new deal on dementia" prioritises investment in innovation to develop and test scalable solutions to meet the needs of people affected by dementia. In this presentation we will share the Society innovation sprint model, an accelerated innovation process, working through 4 stages, Learn, Investigate, Find, and Experiment to co-create solutions to unmet needs. Desk research, stakeholder and audience interviews were conducted to inform development of four insight statements to be used as springboards at a co-creation workshop. These statements recognize the lack of understanding about the effect dementia might have on sex and intimacy needs of people living with dementia and how these needs can be met; the lack of clear and consistent policy in meeting needs; how unprepared care staff are; and the difficulties of speaking about, understanding and meeting sex and intimacy needs. Several solutions which meet these needs will be presented along with an update on and plans for wider adoption





POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-005

PUTTING THE NEEDS OF THE PERSON WITH DEMENTIA, AND THEIR CARERS, FIRST: RESEARCH DRIVING CHANGE

Jennifer F Thompson^{*1,2}; Maria Crotty³; Sue Field⁴; Craig Sinclair⁵; Simon Biggs⁶; Meera Agar^{7,8}; Joan Jackman⁹; Sally Grosvenor^{1,2} and Susan Kurrle^{1,2}, (1)Cognitive Decline Partnership Centre, Sydney, Australia, (2) University of Sydney, Sydney, Australia, (3)Flinders University, NHMRC Cognitive Decline Partnership Centre, Adelaide, Australia, (4)Western Sydney University, Sydney, Australia, (5)University of Western Australia, Perth, Australia, (6)School of Social and Political Sciences, The University of Melbourne, Melbourne, VIC, Australia, (7) University of Technology Sydney, Sydney, Australia, (8)Hammondcare, Sydney, Australia, (9)Dementia Australia, Canberra, Australia

Abstract:

Improving the quality of life and wellbeing of people living with dementia and associated functional decline requires co-creation and knowledge translation to implement changed policy, systems, and practice. The Australian Government's National Health and Medical Research Council (NHMRC) Partnerships for Better Health Initiative has brought together clinicians, consumers, researchers, aged care providers and decision makers to better implement research outcomes into health and health system improvement. The Partnership Centre on Dealing with Dementia and Related Functional Decline on Older People (Cognitive Decline Partnership Centre or CDPC) is a working example of this model in practice.

The release of the CDPC funded Clinical Practice Guidelines and Principles of Care for People with Dementia in Australia has seen a significant change in the understanding of what it means to provide best practice care for people with dementia around Australia. Involving consumers in its development, and containing 109 recommendations, these Guidelines are influencing clinical practice, directing government funding initiatives, and informing health and aged care services. Over 1400 copies of the associated Consumer Companion Guide, developed also with the assistance of consumers, have been disseminated into community, health services, and aged care services, providing a clear language guide for people with dementia about the level of clinical care they should expect.

The CDPC's primary aim is to improve the lives of people with dementia and their families. CDPC research outcomes are already influencing policy through submissions to the NSW Law Reform Commission into Elder Abuse and NSW Law Reform Commission Inquiry into the Guardianship Act 1987. The Centre is informing older Australians about the importance of Powers of Attorney through a series of community seminars across the state of New South Wales, and numerous CDPC developed resources including fact sheets and videos to assist the person with dementia and their family plan for their ongoing health and future are now available.

The partnership model of the CDPC gives researchers, consumers, and the providers themselves a unique opportunity to examine Australian aged care service systems and practice. The CDPC has a number of projects aimed at improving care within services including: providing detailed information in the areas of cost of delivering care for a person with dementia; improved and new models of care; and the role of regulation in the aged care system.

Co-funded through government and industry, the CDPC has supported thirty-four research activities and a number of workshops aiming to bridge a knowledge gap between evidence and practice and create implementable research outcomes. The examples being presented will illustrate how putting the person with dementia 'first' is enabling successful implementation for this research partnership model that is developing and communicating research to improve the quality of life and well-being of the person living with dementia.



Well-being and quality of life - Poster

P02-006

ROLE OF EDUCATION IN THE EFFECT OF SUBJECTIVE MEMORY ON SOCIAL CONTACT

Dr. Jung-Hwa Ha*, Seoul National University, Seoul, Korea, Republic of (South) and Manacy Pai, Kent University, Kent, OH

Abstract:

Objective: This study examines the extent to which education moderates the effect of subjective memory problems on social contact with children and friends.

Method: Using the 2014 wave of the Health and Retirement Study (HRS), a nationally representative panel survey of adults aged 51 and over in the US., we conducted hierarchical regression analyses, estimating the effect of subjective memory problem on contact with children and friends and the moderating effects of education.

Result: While those with higher education report more social contact with children and friends compared to peers with fewer years of education, when they have subjective memory problems, highly educated people report decreased interactions with children and friends. That is, the negative effect of subjective memory problem on contact with adult children and friends is more pronounced among those who are college educated compared to their peers without college education.

Conclusion: While education may serve as a resource for social engagement, when one has memory problems, those who are highly educated may be more vulnerable to stigma associated with memory loss.





POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-007

DEMENTIA ADVISERS - CREATING A MORE EFFECTIVE, EFFICIENT SERVICE TO IMPROVE QUALITY OF LIFE AND WELLBEING

Zoe Campbell Ms, Commercial Intelligence and Outreach, Alzheimer's Society, London, United Kingdom and
Raj Kapoor Mr*, Commercial Intelligence And Outreach, Alzheimer's Society UK, London, United Kingdom

Abstract:

Information and advice for people who have a diagnosis of dementia is priority. It helps people cope with the impact of a diagnosis^{1 2} and can improve outcomes and reduce stress amongst carers³

Alzheimer's Society Dementia Adviser service provides accessible, accurate information at the point of diagnosis and beyond, supports people to make use of this information and facilitates access to services.

In 2013 a national evaluation by the UK Department of Health found: "Dementia Adviser services had a significant role in enabling people with dementia and carers to re-narrate their lives, finding a new life which... had meaning, value and purpose..."

"...services often filled a gap in support.... had a positive impact upon well-being and quality of life and had resource-saving implications."

In 2016 the New Economics Foundation found that for every pound of investment in our service nearly four pounds worth of benefits are created.

We provide Dementia Advisers throughout England, Northern Ireland and Wales, from a wide variety of community venues. We reach approximately 14,000 people a month however with dementia prevalence in the UK standing at 850,000 and set to rise, we are aware that there are large numbers of people who are not benefiting from the service.

To address this, we explored more efficient methods of delivery. This led to learning and developments in the delivery model which will be shared as part of a presentation.

We are now investing resource into developing this model further. A tier 1 offer comprises over-the-phone triage, support, information provision, signposting and onward referrals. A tier 2 offer is provided for service users with complex needs via phone and home visits. "Keeping in touch" calls conducted by volunteers (usually every three to six months) ensure that the changing requirements of people affected by dementia are met. The focus of the service is on outcomes identification and management ensuring people do not become 'trapped' in the system. Direct GP referrals are a key element.

The new model allows us to understand the requirements of service users better than before which feeds into staff training and publication of information resources – producing a more efficient, effective service in future and allowing us to track changes and trends.

We have created a model that is replicable and which, because it can be based in any setting, could be re-produced in other countries. We would be willing to speak to colleagues interested in finding out more.

¹ Szymczynska, P., Innes, A., Forrest, L., and Stark, C. (2010) Diagnostic and post-diagnostic service provision to people with dementia and their carers with particular interest in remote and rural populations. Stirling: University of Stirling.

² Ward, R., Howarth, M., Wilkinson, H., Campbell, S., and Keady, J. (2012) 'Supporting the friendships of people with dementia', *Dementia: The International Journal of Social Research and Practice*, 11(3): pp 287–303.

³ Brodaty H, Mittelman M, Gibson L, Sear K, Burns A (2009). The effects of counselling spouse caregivers of people

with Alzheimer's disease taking donepezil and of country of residence on rates of admission in nursing homes and mortality. *Am J Geriatr Psychiatry* 17(9): 734–743.



POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-008

IN YOUR SHOES: WE GET IT - THE DEVELOPMENT OF AN INNOVATIVE, USER LED SERVICE IN GWENT, WALES

Kerry Phelps, Local Services - Wales And West Midlands, Alzheimer's Society UK, Blackwood, Pontllanfraith, United Kingdom; Hayley Hogan, Campaigns And Partnerships, Alzheimer's Society UK, Blackwood, United Kingdom and **Raj Kapoor Mr***, Commercial Intelligence And Outreach, Alzheimer's Society UK, London, United Kingdom

Abstract:

In Your Shoes: We Get It is an exciting development for people living with dementia in the Gwent locality in Wales. Following feedback received by people affected by dementia as part of a population needs assessment in the Gwent locality in Wales, 6 themes were identified, with peer support recognised as a key priority:

- It was considered by all participants to be a vital provision in increasing confidence, motivation and independence
- Expertise, knowledge and understanding of support services staff was excellent and beneficial, but a key factor for most in accessing services was the support from other people living with dementia.
- People with dementia want to “give something back” and support other people to come to terms with their diagnosis, accept help and access services.

As a result, it was agreed that one to one peer support led by volunteers who have dementia would be developed and piloted locally based on their expertise and lived experience of dementia. In line with Alzheimer's Society values and behaviours, the aptly-named We Get It (WGI) volunteer role is open to individuals who have a diagnosis of dementia only, the first role specifically for people with dementia. The volunteers will play a key role in supporting someone living with dementia to come to terms with their diagnosis and keep them connected through offering one to one peer support. By taking a personal, warm and engaging approach to their role, WGI volunteers provide friendly, tailored proactive support that aims to empower and enable people with dementia, both volunteers and service users, to live independently and gain confidence in connecting with and learning from others.

This one to one peer support will provide a way of recognising the individual experiences of the people with dementia and working with peers to explore these experiences in 6 individual sessions. This is time limited by nature, offering 6 sessions to the service user. This was agreed to reduce the possibility of creating dependencies which was a concern for our volunteers. Each one to one session will be take place according to need and could be weekly, fortnightly or monthly. Our volunteers will provide support over the telephone or face to face meeting at an agreed time with the service user. They may also meet the person at a group activity to introduce them to other group attendees, if agreed with the role manager. The volunteers have a training programme which has been tailored to what people with dementia felt they needed to feel confident to support others.

Alzheimer's Society will work with people living with dementia to evaluate the impact of this initiative including benefits on well-being and quality of life. The volunteers living with dementia have been integral to the design and development. Their expertise and knowledge will help to ensure that the needs of people with dementia are recognised. This user led project is a best practice example of working as equal partners with people living with dementia. Encouraging people with dementia to volunteer is a key element of our Side by Side service these findings will therefore inform future development of Side by Side ensuring they are sustained. We are also considering if the findings could be used to encourage others to deliver similar initiatives which could include in other countries.



POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-009

A POPULATION-BASED COHORT STUDY COMPARING POTENTIALLY AVOIDABLE HOSPITALIZATIONS AMONG OLDER PEOPLE WITH DEMENTIA AND WITHOUT IN TAIWAN

Li-Jung Ku^{*1}; Jia-Dan Hsu¹; Chia-Hung Tang² and Chung-Yi Li¹, (1)Department of Public Health, National Cheng Kung University, Tainan City, Taiwan, (2)Department of Psychiatry, Tainan Hospital, Department of Health, Executive Yuan, Tainan City, Taiwan

Abstract:

Objective: Previous studies have shown that people with dementia are more likely to have hospital admissions than people of similar age and gender, and the increased hospital admissions of these patients may result from a failure of outpatient management of comorbidities rather than dementia per se. The aims of this study were to compare the difference in (1) all-cause hospitalizations, (2) five potentially avoidable hospitalizations (PAHs, as defined by the Medicare Ambulatory Care Indicators for the Elderly) between people with dementia and controls without dementia in Taiwan.

Method: This study was a longitudinal analysis of Taiwan's National Health Insurance (NHI) database including ambulatory care and inpatient claims from 112,016 elders with dementia and an equal number of propensity-score-matched controls drawn from a 50% random sample of nationwide non-dementia populations in 2011. In addition to comparing the likelihood and total number of all-cause hospitalizations, we estimated the proportion of patients with five PAHs (diabetes short-term versus long-term complications, hypertension, chronic obstructive pulmonary disease (COPD), and heart failure) by logistic regressions to examine the association between dementia diagnosis and an event of avoidable hospitalization in 2012.

Result: Among our sample of people with dementia, their average age was 80 and 58% were female, while their average Charlson Comorbidity Index score was 0.62. The age, sex, and comorbidity matched cohorts had well-balanced characteristics at baseline. Compared to propensity-matched controls without dementia, people with dementia had a significantly higher risk for all-cause hospitalization (OR=1.23; 95% CI=1.16–1.30), higher numbers of hospitalization (IRR=1.26, 95% CI=1.24–1.28). Furthermore, compared with matched controls, dementia subjects were significantly more likely to have PAHs for diabetes short-term complications (OR=1.94; 95% CI=1.72–2.20), diabetes long-term complications (OR=1.27; 95% CI=1.18–1.36), and COPD (OR=1.23; 95% CI= 1.16–1.30), but less likely to have PAHs for hypertension (OR=0.74; 95% CI= 0.56–0.99) and no significant findings on heart failure hospitalization (OR=1.02; 95% CI =0.96–1.09).

Conclusion: Estimating the difference in PAHs among dementia and non-dementia elders was the first step toward reducing the increased risk of admission experienced by dementia elders. Dementia patients were at a higher risk of condition related PAHs in diabetes and COPD compared with matched controls. More attention is needed to care for dementia patients with those chronic conditions to improve quality in care.



Well-being and quality of life - Poster

P02-010

NEEDS AND QUALITY OF LIFE OF PEOPLE WITH MIDDLE-STAGE DEMENTIA AND THEIR FAMILY CARERS FROM THE EUROPEAN ACTIFCARE STUDY: WHEN INFORMAL CARE ALONE MAY NOT SUFFICE

Liselot Kerpershoek^{*}, Department of Neuropsychology and Psychiatry, Maastricht University, Maastricht, Netherlands

Abstract:

Objective: During middle-stage dementia, formal care services are often introduced to augment the support of family and friends. The Actifcare (Access to timely formal care) study investigated the domains and level of needs of people with dementia and their families during the phase in which formal care is being considered, and it also examined whether higher need levels are related to lower quality of life.

Method: From eight European countries (The Netherlands, Germany, United Kingdom, Sweden, Norway, Ireland, Portugal and Italy), a total of 451 people with mild to moderate dementia who were not receiving formal care and their carers participated. Demographic data were collected, and needs were measured with the Camberwell Assessment of Need for the Elderly. Quality of life (QOL) was measured with the QOL-AD, and carer quality of life was measured with the CarerQol. The relationship between needs and QOL was analysed with multiple regression analyses.

Result: Needs were primarily expressed in the domains of psychological distress, daytime activities, company and information. People with dementia rated their unmet needs significantly lower than their carers: the mean number of self-rated unmet needs was 0.95, whereas the mean proxy ratings were 1.66. For met needs, the self-rated mean was 5.5 and was 8 when proxy-rated. The level of needs reported was negatively associated with QOL: for both the person with dementia and the carer, QOL decreased as the number of needs increased.

Conclusion: The study results show that informal carers reported almost twice as many needs as people with dementia. Our cohort consisted of community-dwelling people with dementia who did not yet use formal care, and for whom the informal carer provides most of the care. This might have an influence on quality of life due to its inverse relationship with needs (for the person with dementia and informal carer). The domains in which needs are expressed should therefore be the primary focus for interventions to support QOL in community-dwelling people with dementia and their carers. In addition, the perspectives of people with dementia are informative in addition to those of their carers when identifying and addressing needs.





POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-011

PREPAREDNESS FOR TRANSITIONS IN DEMENTIA CARE: A LONGITUDINAL QUALITATIVE STUDY

Sahdia Parveen¹; Gary Fry²; Val Morrison³; Richard Fortinsky⁴ and Jan R Oyeboode², (1)Centre for applied dementia studies, University of Bradford, Bradford, United Kingdom, (2)University of Bradford, Bradford, United Kingdom, (3)Bangor University, Bangor, United Kingdom, (4)University of Connecticut, Connecticut

Abstract:

Objective: As the population continues to age, an increasing number of relatives will be relied upon to provide care and support for a family member living with dementia at home. However, little is known about how willing and prepared individuals are to provide care. Previous research with stroke survivors and family caregivers has found that caregiver preparedness is related better outcomes for the care recipient and caregiver. Within the context of dementia, families experience a number of transition points such as receiving a formal diagnosis, making legal and financial decisions, movement between locations of care and end of life care. However little is known about how prepared caregivers feel about these transitions and what would enable them to feel more confident and prepared to manage challenging transitions in care.

Method: A total of 21 caregivers participated in an in-depth interview at the first time point; six months later 19 of the caregivers agreed to be interviewed again; and 17 of the caregivers participated in the final interview 12 months later.

Result: Thematic analysis was conducted with a focus on factors that contributed to caregivers' feelings of preparedness during a transition. The caregivers experienced a range of transitions during the study including: having recently received a formal diagnosis, changes in the carers' circumstances and health, the person with dementia being diagnosed with other health conditions, the person with dementia developing behaviours that challenged the caregiver, the person with dementia moving into nursing care and the death of the person with dementia. Factors that influenced caregiver preparedness included: attitude towards preparing and planning, existing knowledge and understanding of dementia, access to support (information and services) and progression of care needs.

Conclusion: The study has implications for the development of time specific interventions to prepare caregivers for transitions in caregiving.





POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-012

OPTIMISING HEARING-RELATED COMMUNICATION AND SOCIAL INTERACTION TOWARDS ENHANCED QUALITY OF LIFE FOR CARE HOME RESIDENTS WITH DEMENTIA: A REALIST SYNTHESIS

Brian Crosbie^{*}, Division of Psychiatry and Applied Psychology, University of Nottingham, Nottingham, United Kingdom; Melanie Ferguson, NIHR Nottingham Biomedical Research Centre, Nottingham, United Kingdom; Geoff Wong, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom; Dawn-Marie Walker, Health Sciences, University of Southampton, Southampton, United Kingdom; Stevie Vanhegan, University of Nottingham, Nottingham, United Kingdom and Tom Denning, School of Medicine, University of Nottingham, Nottingham, United Kingdom

Abstract:

Objective: Better hearing communication is strongly related to the quality of life for residents with dementia living in care homes. Although it is a common problem, often affected by noisy care home environments, the communication needs of residents with dementia and hearing loss are largely unmet. Research shows that hearing aids can enhance communication. However, individuals with dementia often don't tolerate wearing them, and there is scarce attention paid to the monitoring of residents' hearing related communication needs. In addition, there is a dearth of dementia focused communication training provided for care home staff. These problems compound staff views that hearing loss is the inevitable result of ageing, with little that can be done about it. Thus low priority is given to managing individuals' hearing communication. This can result in isolation, depression and reduced quality of life among residents as their social interaction diminishes. The objectives of the ORCHARD study was to understand the issues that stand in the way of optimizing hearing communication, to inform future research, and offer solutions by way of informing practice guidelines.

Method: To address hearing-related communication in care homes, we conducted a realist synthesis (RS). As a theory-driven approach to reviewing literature, it also uses expert opinion to understand complex health situations. Using RS we developed a theory surrounding the management of hearing-related communication in care homes. Applying formal processes to the literature search and data extraction, the analysis uncovered relevant mechanisms and contexts to help confirm, refute or refine our understanding of how hearing communication could be improved.

Result: Our review findings indicate that improving hearing communication by taking a person-centered approach would enhance the quality of life of people living with dementia. A positive care home culture gives front line staff 'permissions' to work towards enhanced hearing communication through a series of mechanisms. These mechanisms are elaborated in five conceptual areas of care home delivery. They include leadership towards positive regard for residents and staff; communication training for staff; knowing the person & responsive awareness; monitoring hearing communication; managing noise in the environment.

Conclusion: Positive leadership, providing appropriate training and resources, is likely to enhance staff skills. Leading to staff feeling able and equipped to address the hearing communication needs of residents, towards enhanced interactions and raised quality of life. The synthesis will be used to inform guidelines in hearing-related communication and identify research priorities with a focus on practical interventions.



POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-014

HOW THE WELLBEING AND QUALITY OF LIFE BENEFITS OF SINGING FOR THE BRAIN CAN BE REPLICATED ACROSS COUNTRIES

Zoe Campbell Ms, Commercial Intelligence and Outreach, Alzheimer's Society, London, United Kingdom and Sally Copley*, Policy, Campaigns and Partnership, Alzheimers Society, London, United Kingdom

Abstract:

Research facilitated by Alzheimer's Society and conducted by the University of Reading, showed that people with dementia, for whom spoken response and communication in general becomes problematic, become actively involved in vocal expression through singing, especially familiar and well-known songs.

Using these research findings, we have developed a successful service model: Singing for the Brain® (SftB) which produces social and therapeutic benefits. An evaluation conducted in 2012 showed that: "People who use the Singing for the Brain® services felt that the service had a positive impact on their lives and reported improvement in confidence and communication."

Over the past 14 years we have gone on to deliver SftB across England, Northern Ireland and Wales providing a strong evidence base of efficacy. Today 5,000 people every month take part in our SftB services. However, with the dementia prevalence rate in the UK currently standing at over 800,000 and set to rise, we are aware that only a small fraction of people affected by dementia are benefitting from SftB.

There are resource implications of directly delivering more SftB services which make it difficult for us to simply run more services ourselves. We have therefore explored alternatives we could employ to ensure SftB provision grows

During 2016 we conducted market research and literature reviews of evidence into how some social impact organisations have been able to replicate their proven models at scale. This research showed that SftB is ripe for social replication. Social replication is about reproducing a successful social purpose service in other geographic areas to dramatically increase impact and reach. Done correctly, replication can contribute toward the alleviation of social problems on a large scale.

SftB follows an established structure including regular sessions of a pre-defined format, delivered by trained facilitators. This means the benefits are only realized by following this model exactly, but we can instruct and support others how to deliver it successfully themselves.

Further work was conducted during 2017 - engaging with charities who have adopted social replication in other fields, (for example the Trussell Trust who use a social franchise model to tackle food poverty); to see if these methods can be used in dementia services; to identify risks and with a specialist Solicitor to explore the legal implications.

As a result of this work, we have begun to develop a social replication offer which will allow us to spread the delivery and benefits of SftB at scale, in a cost effective manner whilst managing potential risks. This offer will be launched during 2018/19.

As part of the development, we have supported two organisations in Singapore to develop their own versions of the SftB service, showing that we can successfully transfer the model to other countries and cultures as well as within the UK.

We believe the work we have done to develop a social replication model will be of interest to other countries as it offers an efficient, proven way to extend the reach and impact of demonstrated services.

We are willing to speak to colleagues from around the world who are interested in finding out more about Singing for the Brain® or to learn from our work to develop a social replication model. If successful the presentation will include footage of a SftB session.



POSTER ABSTRACTS

Well-being and quality of life - Poster

P02-015

MEMORY ADVICE – ADVICE AND GUIDANCE BY PHONE FOR PEOPLE WITH MEMORY DISEASES AND THEIR FAMILIES

Jasmiina Jokinen* and Mailis Heiskanen, Alzheimer Society of Finland, Helsinki, Finland

Abstract:

There are around 200,000 people with memory-related diseases in Finland. Annually, 14,500 people are diagnosed with a progressive memory-related disease. People with memory diseases and their family and friends are a special group to whom equal access to services and customer-oriented advice and guidance are particularly important. Timely advice, guidance and support can help a person with a memory disease to live safely in their own home and stay there longer.

The aim of the Memory Advice phone service is to help ensure safe and individual lives for people with memory diseases. It offers timely and comprehensive information and advice for people with memory diseases and their families.

The advisers are professionals in the field of memory diseases, and belong to the Alzheimer Society's network of professionals. The Alzheimer Society of Finland coordinates the phone service, and offers advisers training according to the needs and requests that arise during calls.

The Memory Advice phone service is open three days a week. The Swedish-language service is open once a week. Swedish-speaking people comprise around 5% of the Finnish population. Considering the nature of memory-related diseases, it is important that advice is available in the family's first language.

There are around 800 calls a year, around half of which are answered – this is because most conversations are fairly long. The caller is usually a family member, the diagnosed person, or a professional. 80% of callers are women. The biggest age group is 41 to 65-year-olds.

The questions are most often about the symptoms and treatment of memory-related diseases, the patient's challenging behaviour and assistive devices and locating technology. The themes also include family members' ability to cope, driving ability and legal advice. Around 70% of legal advice phone calls are about the continuing power of attorney, 20% are about the advance directive and 10% concern other issues.

According to the feedback surveys completed by the callers, Memory Advice offers timely information and support to recently diagnosed patients and their families in particular. Families are provided with individual advice and guidance, as well as information about the disease, treatment and service systems, rehabilitation and assistive devices. The phone service also directs families to memory associations and the support and activities they provide.

Many callers like the fact that they received guidance in accordance with their needs. A special mention was given to the advisers' expertise, the calm tempo of their conversation and their pleasant advisory style.





POSTER ABSTRACTS

Carer support and training - Poster

P03-001

NATIONAL DEMENTIA STRATEGY IN ACTION: BETTER CARE AND SUPPORT FOR PEOPLE WITH DEMENTIA AND CARERS

Stefanija Lukic Zlobec and **David Krivec***, Spominčica - Alzheimer Slovenia, Ljubljana, Slovenia

Abstract:

Until 2009 dementia was not discussed in Slovenia. In 2009, National Strategy for dementia was launched. Two specialists in the field of dementia and a representative of Spominčica - Alzheimer Slovenia and family carer of younger onset dementia husband took initiative for this Strategy, which received support from Parliamentary Health Board. At Alzheimer Europe debates we realized the growing need for a wide public campaign to prepare a National Dementia Strategy. Since, Spominčica successfully promoted the need through its nationwide activities such as Alzheimer Cafes, support groups, education and training programs, Spominčica magazine, etc.

In the next years the working group prepared the Dementia Strategy. In May 2016 Minister of Health signed the Strategy. The strategy focuses on individual and his needs through achieving three goals: early diagnosis, access to treatment and therapy and coordinated support. In the next month the activities to prepare the Dementia Strategy Action Plan started. In 2017, the Action Plan was prepared. The action plan focuses on to achieving the goals with setting specific actions for defined agencies and actors. The actions are prepared by three subgroups comprised by relevant stakeholders, health, social welfare and research, and education.

Spominčica has strengthened its public campaigns of raising awareness about dementia and creating a dementia friendly society. In 2017, Spominčica and Slovenian Human Rights Ombudsman opened the first Dementia Friendly Spot in Slovenia. It is a place, where persons with dementia, their care partners, public workers and other members of the community can get information on dementia, needed support and help. Dementia Friendly spots provide help for persons who show symptoms of dementia, are lost or confused. This initiative also facilitates social inclusion of persons with dementia and their care partners in the community. The interest for Dementia Friendly Spots is growing, in 2018, Spominčica will open more than 35 Dementia Friendly Spots across Slovenia.

In response to the Strategy and Action Plan, in 2017 the Ministry of Health for the first time issued a call for public tender for dementia. The goal of the project is the implementation of training programs for GPs, and formal and informal care partners. We collaborate better and better with the Ministry of Health and the Ministry of Social Affairs.

Spominčica is also involved in several European projects. One project is MOPEAD (Models of Patient Engagement for Alzheimer's Disease), where we are the only NGO among 14 partners. We are also partners in AD-GAMING and AD-AUTONOMY projects by Erasmus+ and in AAL project IONIS.

With all our activities we succeeded to raise awareness and reduce stigma about dementia. We significantly contribute to the improvement of the conditions in care homes, especially in the departments for persons with dementia. Our care homes are also very much involved in local communities.



POSTER ABSTRACTS

Carer support and training - Poster

P03-002

VIRTUAL REALITY EXPERIENCES IN DEMENTIA CARE EDUCATION AND SUPPORT FOR INFORMAL AND PROFESSIONAL CAREGIVERS

Claudia van der Velden^{*1}; Marije Kaat^{*1}; Bernadette M Willemse²; Marleen Prins³; Marjolein Veerbeek² and Astrid van der Schot², (1)Program on aging, Trimbos Institute, Netherlands Institute of Mental Health and Addiction, Da Costakade 45, Utrecht, Netherlands, (2)Trimbos Institute, Netherlands Institute of Mental Health and Addiction, Utrecht, Netherlands, (3)Department on Aging, Trimbos Institute, Netherlands Institute of Mental Health and Addiction, Utrecht, Netherlands

Abstract:

Background Virtual Reality (VR) creates immersive experiences that can be used to provide support for informal caregivers (1) and to educate (care)professionals (2). The primary objective is to increase understanding and compassion for people with dementia. By integrating these immersive experiences in support and education, we aim to achieve a more person-centered approach of informal and professional caregivers. This enhances the well-being of people with dementia, by placing the person with dementia and his/her personal needs central.

Objective With this poster we present the first experiences of two products with this type of immersive experiences. First, the content and results of Through the D'mentia Lens (TDL) for informal caregivers, a product that already exists, will be presented. Second, the development and first prototype of a new interactive VR-product for (future) healthcare professionals will be illustrated. Both VR-experiences will be available to participants at the conference.

Interventions*1) Through the D'mentia Lens (TDL)*

To enhance understanding and compassion of informal caregivers, a VR-experience accompanied by an e-learning was developed in 2016. TDL was then pilot tested and implemented in practice. Recently, the 360 degree movie was translated to an English version and the e-learning was adapted, making it also suitable for (future) professional caregivers.

Content TDL

The script of TDL is based on an existing real-life intervention called 'Into D'mentia' and was supplemented with new input of a group of informal caregivers. TDL is a 360 degree movie. After watching the VR-experience, guided by a professional, the user receives a code to access the e-learning at home. The e-learning aims to deepen the experience.

Results

In a pilot study (N=40), the usefulness, ease of use, satisfaction and acceptability were evaluated positively by informal caregivers. Additionally, person-centeredness and perspective-taking increased significantly. Also, perceived competence, resilience and pro-activity and positive dyadic interaction increased significantly.

2) Interactive VR-experience for care professionals

The second immersive learning experience is developed to enable (future) healthcare professionals to learn how their behavior affects the well-being of people with dementia and how to provide person-centered care. Development of this learning experience will be finished later this year.

Content VR-experience

This experience consists of animated VR-scenes in which the user can interact with the VR-environment. The user comes across multiple decision points and experiences the consequences of the choices that were made. The choices that the user makes in the VR-scene will tailor the content of the particular lessons in the



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accompanying e-learning. Professionals will learn what the effects of their own behavior are on the behavior and mood of people with dementia. The VR-experience can be done independently by healthcare professionals without face-to-face guidance, which makes this VR-experience inexpensive and relatively easy to distribute widely.

User test

The VR-experience will be tested by users (care professionals). Their input will be used to further develop and adjust the VR-experience. A pilot-study will be carried out to investigate the impact of the VR-experience on different aspects. A process evaluation will provide insight into the feasibility and acceptability of the VR-experience.





POSTER ABSTRACTS

Carer support and training - Poster

P03-002

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In a pilot study (N=40), the usefulness, ease of use, satisfaction and acceptability were evaluated positively by informal caregivers. Additionally, person-centeredness and perspective-taking increased significantly. Also, perceived competence, resilience and pro-activity and positive dyadic interaction increased significantly.

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POSTER ABSTRACTS

This experience consists of animated VR-scenes in which the user can interact with the VR-environment. The user comes across multiple decision points and experiences the consequences of the choices that were made. The choices that the user makes in the VR-scene will tailor the content of the particular lessons in the accompanying e-learning. Professionals will learn what the effects of their own behavior are on the behavior and mood of people with dementia. The VR-experience can be done independently by healthcare professionals without face-to-face guidance, which makes this VR-experience inexpensive and relatively easy to distribute widely.

User test

The VR-experience will be tested by users (care professionals). Their input will be used to further develop and adjust the VR-experience. A pilot-study will be carried out to investigate the impact of the VR-experience on different aspects. A process evaluation will provide insight into the feasibility and acceptability of the VR-experience.





POSTER ABSTRACTS

Carer support and training - Poster

P03-004

A SURVEY EXPLORING THE EDUCATIONAL NEEDS OF DEMENTIA CAREGIVERS IN GREECE

Vasiliki Exarchakou¹; Eleni Dimakopoulou¹; Areti Lioupa²; Eva Ntanas¹ and Ms. Paraskevi Sakka¹, (1)Athens Alzheimer Association, Athens, Greece, (2)CMT PROOPTIKI, Athens, Greece

Abstract:

Objective: Caregiving is a highly demanding and stressful task affecting social, financial and health status of caregivers (Brodaty & Donkin, 2009, Alzheimer's Association, 2017). Education is a valuable tool for caregivers in order to sufficiently fulfil their role. Recent studies demonstrate that caregivers need more information and training in order to increase their caregiving skills (AARP Caregiving in the U.S., 2015 Report). The aim of the present study was to explore dementia caregivers' educational needs in Greece, so that effective training programs could be designed for them.

Method: The survey was conducted by Athens Alzheimer Association between May and July 2017. A structured questionnaire was administered to caregivers through the web or face to face interviews. Participants were living in Athens and other greek cities. Demographic characteristics (age, sex, region of residence, occupation status, education level etc.) were recorded. Survey responses regarding caregivers' educational needs were analyzed using IBM SPSS 24.

Result: 580 caregivers (150 male, 430 female) participated. 55.7% aged between 46-65yrs, 75.5% were living in Athens, 29.7% had a university degree. 43.8% of the caregivers were living in the same house with the person with dementia and 32.2% were sharing caregiving tasks. The vast majority of participants (90.9%) considered training to be of major importance. 51.6% had already sought information about dementia caregiving, with 79.2% not having been satisfied with the results of the search. Approximately 40% of the caregivers had attended some form of caregiving training, presentations or seminars. Region of residence, sex, age, occupation status, relation with the person with dementia and being the principal caregiver were associated with participation in educational programs. Popular topics of educational interest were "Coping with practical issues", "Information about Alzheimer Disease and dementia, latest scientific developments" and "Non-pharmacological interventions".

Conclusion: Dementia caregivers highly appreciate and need training programs, despite existing barriers. Physical attendance was desirable but distance learning programs through innovative technologies could also support the educational needs of caregivers. The results of our survey suggest that careful consideration of caregivers' characteristics, unmet needs and interests could lead to the development and implementation of more and better caregivers' training programs by State authorities, Alzheimer Association's etc.





POSTER ABSTRACTS

Carer support and training - Poster

P03-005

EXPLORING THE EFFECTIVENESS OF 'VALUE-BASED EMOTIONAL-SUPPORTING GROUP PROGRAM' FOR FAMILIES LIVING WITH DEMENTIA

Mr. Po-Chieh Lin^{*1}; Yu-Chun Chi¹; Yi-Jhen Lee¹; Chi-Cheng Yang²; Da-Chen Chu¹ and Sheng-Jean Huang¹, (1) Taipei City Hospital, Taipei, Taiwan, (2) National Chengchi University, Taipei, Taiwan

Abstract:

Objectives: Many programs are developed for serving families with dementia, but most of them focus on providing healthcare information. In fact, there is a lack of group programs solving the emotional issues of families. The purpose of this study is thus to develop a value-based emotional-supporting program and to examine its effectiveness in reducing negative emotions in the families.

Methods: This emotional-supporting group recruits five families of people with dementia who had been followed in the outpatient department regularly. The emotional-supporting group was held once a week for 5 sessions, and each session lasted for 60 minutes. Psychologists use expressive art material to promote families recount their life stories, and families were invited to fill in the "Chinese Caregiver Burden Inventory" and the "The Holistic Supportive Relationship Scale," to evaluate their emotional status.

Results and Conclusions: In this study, five families unanimously confirmed that the presentation of personal feelings triggered by expressive art material can reduce the negative emotions and strengthen the willingness to continue to use psychological services in the future. This study found that the value-based, people-centered group care is necessary for family members of dementia.





POSTER ABSTRACTS

Carer support and training - Poster

P03-006

EXPERIENCE OF CARE ABOUT MALE CAREGIVERS FOR THE PERSON LIVING WITH DEMENTIA

Shu-Hui Liang^{*}, Long-Term Care, National Taipei University of Nursing and Health Services, Taipei, Taiwan

Abstract:

The number of people living with dementia increases year by year in Taiwan, the number of male caregivers nowadays tends to also increase with the change of social work patterns and family structures. Due to national conditions or the cultural differences between East and West, there are different challenges and experiences in dementia care. This study explored the caregiving experience of male family caregivers in caring for the understanding of the feelings of the male caregivers in the care process and the influencing factors of the feelings. In this study, qualitative research was used to collect data through in-depth interviews. According to interviews and recordings after the interviews, data analysis was conducted by content analysis. This study interviewed 6 male caregivers who including two husbands and four sons, their mean age was 60 years old. The study found that male caregivers maintain the balance of the family in the caregiving process. They play a caregiving role and also act as the head of the family. The married son caregiver has his wife to assist in the meals for the relative with dementia, and his primary responsibility is to accompany with relative with dementia to exercise and to observe the dementia's condition. Because of taking care of relative with dementia, the single male caregivers are more difficult to enter the marriage. Single sons feel more caregiving barriers due to gender differences when they take care a mother with dementia.





POSTER ABSTRACTS

Carer support and training - Poster

P03-007

FAMILY AND INDIVIDUAL PATHWAYS OF ALZHEIMER'S DISEASE

Ms. Elizabeth A. Spencer*, College of Communication and Information, University of Kentucky, Lexington, KY

Abstract:

Life does not happen in a bubble. Pathways across the life course are intertwined and interdependent on intrapersonal and interpersonal levels (Elder, 1995). Individual trajectories are intertwined and interdependent with the pathways of others. Family members are interdependent and linked across time (Marks, Lambert, June, & Song, 2008). Contextual factors relating to aging parents impact adult children's wellbeing. A terminal illness diagnosis for an aging parent can negatively impact an adult child's mental and physical health (Marks et al., 2008). This research design seeks to investigate the juxtaposition that what health professionals' are encouraging caregivers to do is increasing physical, mental, and relational health risks; and does this put caregivers at greater risks of developing dementia themselves.

Every three seconds, someone in the world develops dementia (ADI, 2018). Not only is this pervasive disease impacting an immense number of people, but also their families. In the United States, there are 15.9 million unpaid Alzheimer's disease and dementia caregivers, most of whom are family members (AA, 2017a). Many of these familial caregivers are balancing the needs of not only the person living with dementia, who is often an aging parent, but also the needs of their own family unit.

Family caregivers face unique challenges with a dementia diagnosis (NAC, 2017). The impact of caregiving on family members is great. Compared to 17 percent of non-dementia diagnoses for persons of advanced age, 35 percent of dementia caregivers report that these responsibilities have negatively impacted their own health (AA, 2017a). As family members navigate the process of giving care to the person living with dementia, they must also maintain relationships with each other.

The quality and timing of social relationships impact psychological health (House, Landis, & Umberson, 1988). Low quality social relationships can impact an individual's health similar to the degree that negative behaviors (e.g., tobacco use, obesity, and cardiovascular disease) have. Family science scholarship has examined the impact of marital relationships and parenthood on individual stress, well-being, and overall health (Hagestad & Call, 2007; Umberson et al., 2006; Umberson, Pudrovskaya, & Reauck, 2010). Long-term marital strain has a cumulative negative effect on health in that it creates a susceptibility as individuals age (Umberson et al., 2006). The experience of parenthood is a transformative one (Nomaguchi & Milkie, 2003) that imposes "a unique mix of stress and rewards for those who enter" as Umberson et al. (2010) posit.

This research design proposes a study to examine life course factors that lead to the diagnosis of Alzheimer's disease. Additionally, pathways to filial caregiving will be examined. Trajectories such as social relationship (i.e., marriage, family, support networks, etc.) quality, the timing of parenthood, and contextual factors are imperative to consider when examining these issues. This proposal seeks to investigate the pervasiveness of Alzheimer's disease, familial caregiving roles, and the interwoven nature of linked lives within the framework of Life Course Theory (Elder, 1995). In particular, the pathways to Alzheimer's diagnoses will be examined. Potential findings from this research could hold strong practical, theoretical, and methodological implications.



POSTER ABSTRACTS

Carer support and training - Poster

P03-008

UTILIZATION AND USABILITY OF REGIONAL DEMENTIA CARE STRUCTURES - BARRIERS AND SUPPLY GAPS

Astrid Linke*; Mrs. Liane Schirra-Weirich and Hannah Groeber, Center for Participation Research, Catholic University of Applied Sciences, Cologne, Germany

Abstract:

Objective: Most people with dementia are provided for at home by family caregivers. As a result, family caregivers face different impacts because of diverse challenges (e.g. organization of care structures, bureaucracy). Therefore needs of family caregivers have to be taken into account to strengthen and stabilize home care arrangements. The project 'utilization and usability of regional dementia care structures' (regional research project) analyzes if family caregivers use support structures including various perspectives. Aims of the project are to identify differences between urban and rural regions, barriers of usability and to develop appropriate care structures.

- **Method:** Arrangement: literature research/ preparation of inquiries: utilization and usability, inhibition levels and barriers, allocation and access, rural-urban differences
- Three focus groups (n=16); caregivers, providers, political actors; Topics: analyzing relevant perspectives, utilization and usability of support services, barriers, supply gaps
- Online-Survey: Providers (n=21); analyzing existing structures of dementia care services
- PAPI-Survey: Caregivers (n=44); user-specific behavior and attitude patterns; utilization of support services

Result: Stakeholders state in the focus groups that there are several supply gaps. Especially two groups were mentioned in each focus group. First, people with younger onset dementia have no specific care structures. Second, aged caregivers are insufficient provided for as well. In both situations, the care arrangements are unstable.

Concerning structural problems it could be determined that not dementia as a state but more the organization of care is the highest challenge. Therefore, problems of bureaucracy, communication with public authorities, health and care insurance etc. can emerge.

In both surveys (providers, family caregiver), barriers of utilization were inquired. The results show that providers see barriers more on an individual level, such as bad conscience to accept help, caregivers do not want to get help or bad experiences with services (regarding caregiver). From the caregiver's perspective, the problems are rooted in the system and structure (missing flexibility, bureaucracy, long access routes).

Conclusion: Due to the adjustment of the user and provider perspective it was possible to identify supply gaps (e.g. for young-onset dementia) that providers have to create new structures for. One challenge will be to find out which possibilities providers have to develop those structures. To reach people in rural areas and aged caregivers who do not use any service structures so far, low-threshold methods are needed. Parishes, clubs and associations that the target group is using could be useful in this regard. Interface problems have to be reduced to improve the flow of information between the actors by independent advice centers. Regional oriented service structures can be a solution to establish suitable services.



POSTER ABSTRACTS

Carer support and training - Poster

P03-009

“10 EARLY SIGNS OF DEMENTIA” INDIFFERENT SETTING AND SERVICES IN COMMUNITY

Chun-Yi Yang^{*1}; Ya-Hui Liang²; Hui-Ya Lin³; Zhong-Han Lee³ and Dr. Chien-Liang Liu², (1)Social work, Taipei City Hospital, Taipei, Taiwan, (2)Dementia Center, Taipei City Hospital, Taipei, Taiwan, (3)Zhongzheng District Health Center, Taipei, Taiwan

Abstract:

Objectives: Dementia is a collection of symptoms that can be from Alzheimer's disease or a variety of possible diseases. In different places and situations, people with dementia would express different behaviors which could be early signs of dementia. In order to early detect and early diagnosis of dementia, developing the place specific early signs of dementia is useful.

How to do?

In order to develop the 10 early signs of dementia in different situations, we consulted the expert in different field and interviewed the worker in different institutes to understand what are the common situations they had experienced when serviced people with dementia.

We provide the dementia symptoms detection training courses to the following identified locations such as healthcare services, banks, post offices, supermarket, pharmacy, community dementia services site, police station, fireman station, museum, and so on. We incorporate the service of early detection and screening by AD8 through volunteer at site. In the meantime, the case managers of collaborative dementia care center provide rapid response services and training courses for all institutes. All the dementia suspected person would be provided the service of rapid diagnosis and would be following up by case managers.

Conclusion

We provided 10 specific early signs to above mentioned locations which can allow institutes to efficiently service the person who has suspected dementia symptoms. All the suspected had been transferred and provided further assessment and evaluation.





POSTER ABSTRACTS

Carer support and training - Poster

P03-010

SERVICE USER LED 'DEMENTIA CARE HOME REVIEW' AT SIR SAMUEL KELLY EVENTIDE HOME, BELFAST, NORTHERN IRELAND: A JOINT PROJECT BETWEEN THE SALVATION ARMY AND THE DEMENTIA TRAINING COMPANY

Tim Forester Morgan, The Dementia Training Company, Newport, United Kingdom

Abstract:

This presentation will help delegates understand how The Dementia Training Company (DTC) has been supporting The Salvation Army with the development of best Dementia Care Practice across its 'Older Peoples Services' in the United Kingdom for the last 5 years.

The presentation will provide opportunity to explore how this collaboration has led to DTC being commissioned to carry out a service-user led 'Dementia Care Setting Review' at Sir Samuel Kelly Eventide Home (SSKEH) in Belfast, Northern Ireland.

DTC has developed a robust review process which is designed to identify and, where necessary give guidance and make recommendations for best practice by combining respected dementia specific tools and approaches with innovative experiential evidence gaining opportunities. The entire process has a clear service user involvement ethos.

Delegates who attend this presentation will gain insight into each element of the assessment included in the review process and how when combined, help identify how and where providers should align their service with best practice.

During the presentation we will share the before and after outcome 'benchmarking' measurements and any evidence of the review process's impact on the home and on staff development/practice.

We will share a power point presentation showing before and after photos of the care environment to help reinforce the effectiveness of this process.

The current Dementia Care Setting Review at SSKEH was launched in May 2017 and is due to conclude in March 2018.

The DTC Dementia Care Settings Review tool is currently being independently assessed and its validity verified by the University of Southampton, UK.

All available outcome information from the SSKEH Review and any outcomes from the independent assessment and verification process would be shared at this Conference.

Section 1, Article 8 of the European Court of Human Rights states there is a "Right to respect for private and family life". This applies to all people, including those living with dementia.

We believe that by involving service users in decision-making processes, it is possible to create enabling spaces that nurture and enhance daily living and help to comply with this article.

Our presentation will highlight how this review process:

- Has a philosophy and approach that enables the people on the receipt of care to be informing its provision.
- Adopts multiple approaches to enable us to hear the voices of all the stakeholders (including the residents, family members and care givers) and integrate their views and suggestions into the final report.
- Equips us to listen and act on what we hear.



POSTER ABSTRACTS

Carer support and training - Poster

P03-011

FRONTOTEMPORAL DEMENTIA CARER SUPPORT GROUP - LEARNINGS AND ONGOING ACHIEVEMENTS

Karen Gray Ms*, Client Services, Dementia Australia, Melbourne, Australia and Vivien George Ms, Cognitive Dementia and Memory Service, Barwon Health, Geelong, Australia

Abstract:

Dementia Australia VIC Division and Barwon Cognitive Dementia and Memory Service had been concerned for some time about the lack of accessible and practical support for families caring for individuals with a diagnosis of Frontotemporal Dementia (FTD).

FTD is a degenerative brain disease that gradually destroys the ability to behave appropriately, empathise with others, learn, reason, communicate, and carry out daily activities. FTD typically has a younger age of onset than other forms of dementia and can have a devastating impact on the individual and their family. Carers of individuals with FTD typically report high levels of stress and increasing social isolation owing to the unique and often socially inappropriate behavioural symptoms associated with the disease.

In 2014, a study aimed to establish whether an FTD carer support group could help alleviate carer stress and reduce feelings of social isolation through specialist education and peer support. Twenty-three carers of individuals with FTD participated in a series of monthly 90-minute group sessions facilitated by a Dementia Counsellor and Neuropsychologist. Information about carers' perceived knowledge about FTD and their perceived level of competence in their caring role, as well as their level of social support, and psychological distress, was obtained by structured interview and a series of standardised questionnaires completed pre- and post- intervention. The findings indicated that while carer burden remained "moderate to severe" reflecting the difficult role carers have in managing the daily challenges associated with FTD, carers experienced significantly greater levels of emotional and social support following the intervention and qualitatively reported feeling less socially isolated. Carers indicated that they felt significantly more knowledgeable about FTD and more competent in coping with the day-to-day challenges of their caring role.

This study offered a method of supporting FTD carers in their unique and challenging role, through a peer support group co-facilitated by a Neuropsychologist and a Dementia Counsellor. These two professions offer complimentary areas of knowledge and expertise. The Neuropsychologist provides: education about FTD and the impact on brain function and behaviour specific to the concerns highlighted by carers; explains changes in behaviour and cognition; suggests practical strategies to assist each carer with these changes; and relays the latest research findings. The Dementia Counsellor provides knowledge of carer resources; respite options; and offers strategies regarding relationship, grief and behaviour management issues; and counselling options available.

Four years since the initial study the FTD Carer Group continues as a successful and 'open' peer support program. Carers have a one-to-one in-person session with one of the group facilitators prior to joining the group. This allows for the provision of specific education about the group and the diagnosis of FTD, and to discuss expectations regarding group participation. It is important to explain to potential new participants that group members may be caring for people at different stages of their illness, and that there are different variants of FTD and variable symptomatology.

The success of this FTD Carer Group model has now attracted funding to replicate it in other regions, and to explore its potential for other less common dementias such as Lewy Body Disease and Posterior Cortical Atrophy.



POSTER ABSTRACTS

Carer support and training - Poster

P03-012

TIDE; A SOCIAL MOVEMENT SUPPORTING INVOLVEMENT AND SHIFTING THE BALANCE

Ms. Amanda J McCarren*, Tide, Glasgow, United Kingdom

Abstract:

There is a unique power to people in social movements – one in which purposeful citizens have the determination and courage to stand up, speak out and seek change in the issues that matter to them and their loved ones[1]

tide - together in dementia every day, is the UK wide involvement network for carers and former carers of people living with dementia, hosted by the Life Story Network CIC. At **tide** we are building a social movement of carers capable of bringing about real change.

We see the value in peer support and the potential when investing in the personal development of carers in their own right. Through our bespoke development programme; we give them the tools and confidence to get involved, to influence policy, practice and research and to reframe their experiences to shift thinking which is empowering and leads to better health and well being. Self-efficacy is the belief in one's own ability to successfully accomplish something. It tells us that people generally will only attempt things they believe they can accomplish and won't attempt things they believe they will fail [2]

Carers of people living with dementia are often highly stressed, tired and disillusioned. They face losing their confidence and identity coupled with professionals who don't value or acknowledge their contribution, meaning they are often seen (or not seen as the case may be) as the antithesis of self efficacy. This creates barriers to effective involvement at both a local and national level. Becoming a member of the **tide** network opens up the possibility to break down these barriers

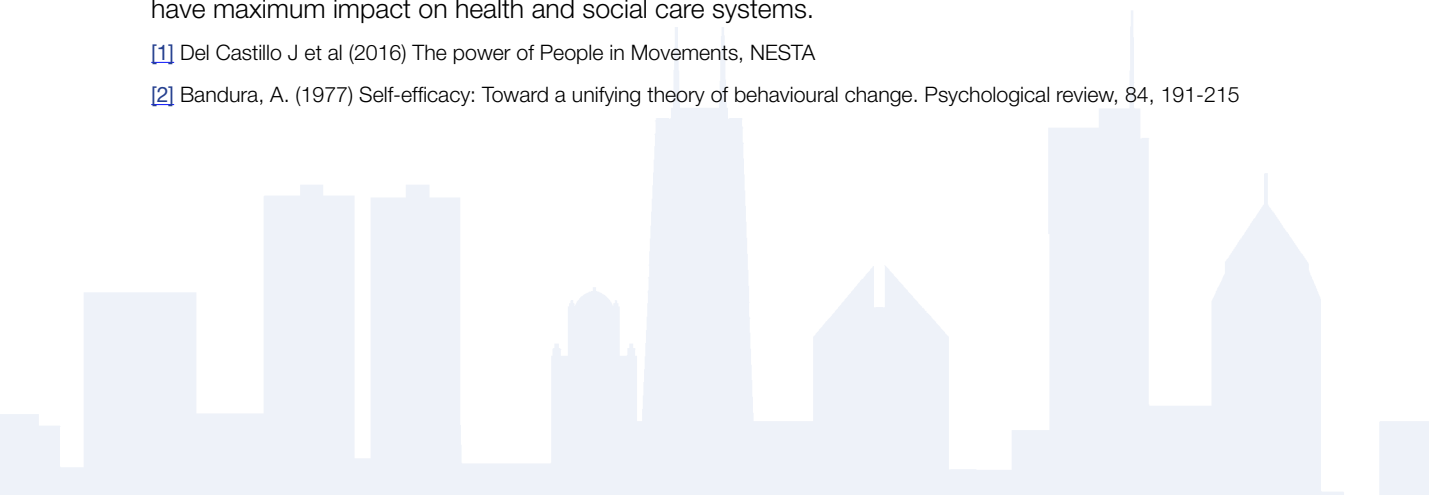
This presentation will showcase the investment from Life Changes Trust in **tide** in Scotland over the next 4 years. Interim results from our external & self evaluation will be presented and combined with carers sharing their experience, impact and personal growth from being involved in **tide**

Delegates will learn how current and former carers can increase their emotional resilience, contributing their expertise through the development programme through our unique involvement network. Delegates will have opportunity to understand why investing in carers is of benefit to carers, people with dementia, commissioners and service providers.

tide will illustrate the critical steps in establishing a social movement and what happens when carers are offered bespoke development opportunities to improve their knowledge and skills, enabling and empowering them to have maximum impact on health and social care systems.

[1] Del Castillo J et al (2016) The power of People in Movements, NESTA

[2] Bandura, A. (1977) Self-efficacy: Toward a unifying theory of behavioural change. Psychological review, 84, 191-215



POSTER ABSTRACTS

Carer support and training - Poster

P03-013

'RETHINK RESPITE': AN INNOVATIVE COMMUNITY PILOT PROJECT FOR CARERS OF PEOPLE WITH DEMENTIA TO IMPROVE KNOWLEDGE ABOUT, ATTITUDES TOWARDS, AND USE OF RESPITE.

Lyn Phillipson Dr¹; Elizabeth Preston Dr²; Keryn Johnson²; Danika Hall Dr²; Elaine Fielding Dr³; Christine Neville A/Pr⁴ and Helen Hasan Prof², (1)School of Health and Society, Faculty of Social Sciences and Australian Health Services Research Institute, University of Wollongong, Wollongong, NSW, Australia, (2)Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia, (3)School of Nursing, Faculty of Health and Dementia Collaborative Research Centre, Queensland University of Technology, Brisbane, Australia, (4)School of Nursing, Midwifery and Social Work, University of Queensland, Brisbane, Australia

Abstract:

Objective: 'ReThink Respite' aimed to address the barriers to respite for people with dementia and their carers. Its objectives were to improve carers' knowledge about, attitudes toward, and uptake of, respite services and strategies.

Method: 'ReThink Respite' was a multicomponent pilot intervention informed by theory, formative research and a co-design process. It supported the re-conceptualisation of respite as part of positive caregiving and of benefit to both carers and people with dementia. Delivered in the Illawarra-Shoalhaven in NSW (Australia) from February 2015 to October 2016 the program supported activities which included: media and awareness raising; education; a website; and decision aids and checklists to support finding and choosing local respite services and strategies. Finally, the program also offered an individualised motivational coaching program which carers and people with dementia could self-select to participate in. A longitudinal survey was used to evaluate carer exposure to project activities and to evaluate changes in: carer knowledge about, attitudes towards, and use of respite services; and carer perceived need for respite, burden, and self-efficacy. Analysis examined between groups differences between those exposed to Community Level Activities (media, website, education) (Group 1) and those who also self-selected to participate in Respite Coaching (Group 2). Analysis of changes over time were conducted through McNemar Test of Change for categorical data, and paired t-tests or Wilcoxon Signed Rank Test.

Result: Preliminary analysis was conducted on n=44/70 eligible carers who completed a survey at two time points [n=26 (Group 1) and n=18 participants, (Group 2)]. Compared to Group 1, Carers in Group 2 who elected to participate in Respite Coaching showed significant improvements over time with regards to their respite knowledge [e.g. '*ability to name three respite services*' (Z= -2.280, p=.023)], positive attitudes (e.g. '*respite services are useful and beneficial to my family member/friend*' (Z= -2.157, p= .031)) and self-efficacy to gain respite [e.g. '*if I want to, I can easily access the appropriate respite*' (Z= -1.994, p=.046)]. They also increased in their intention to use respite [t (17) = -2.335, p=.032] and reported increased levels of personal gain from caring (Z= -2.543, p=.011). Without coaching, carers in Group 1 experienced negative changes with regards to their beliefs that respite services are '*useful and beneficial to my family member/friend*' (Z= -1.977, p=.048); and their ability to '*find organisations that provide services in the community to help them care for their family member/friend*' [t (25)= 2.465, p=.021]. Group 1 carers also showed a decrease in their confidence to '*handle future care problems*' [t (25) = 1.800, p=.016], '*keep their family member or friend as independent as possible*' [t (25) = 1.678, p= .030] and reported a greater degree of '*role captivity*' over the time of the intervention (t (24) = -2.092, p=.047).

Conclusion: This pilot study highlights the potential for one-on-one individualised coaching to enhance community level activities to promote knowledge, confidence and skills relevant to achieving respite. Respite coaching may also be useful to promote personal gain and reduce role captivity over time. Future research should seek to replicate these results using a larger sample and an experimental design.



Carer support and training - Poster

P03-014

HEALTH-PROMOTING SELF-CARE IN FAMILY CARERS OF PEOPLE WITH DEMENTIA

Deborah Oliveira¹; Jim Radburn²; Martin Orrell Prof¹ and **Sarang Kim**^{*3}, (1)Division of Psychiatry and Applied Psychology, University of Nottingham, Nottingham, United Kingdom, (2)Volunteer, Carers in Hucknall, Hucknall, United Kingdom, (3)Research School of Population Health, Australian National University, Canberra, Australia

Abstract:

Objective: Family carers of people with dementia often neglect their own health needs in order to provide care. This has significant impact on their quality of life, use of health care services and ability to provide good care. This study aimed to better understand family carers' unmet health needs, why these needs are unmet and what can be done to help carers look after their own health better.

Method: This study involved a series of qualitative investigations. First, a scoping review of the literature was conducted in July 2017 and eight research experts from many countries were consulted about their current knowledge on this subject. Second, three consultation events with multiple stakeholders (n=50) and four focus groups with carers (n=21) were carried out in Nottinghamshire, UK. The data collected was transcribed verbatim and analysed thematically, following an inductive approach.

Result: There is a limited number of interventions aimed at promoting health-promoting self-care in carers (n=6). The selected studies were mostly carried out in the USA, used small samples and were focused solely on female carers. Research experts believe that this an under-explored area and provided useful information for future research. Qualitative data suggests that family carers are not receiving the support they need, are they receiving enough opportunities for respite breaks, and feel unable to follow a healthier lifestyle or to focus on their own health needs. Family carers need: 1) more opportunities for peer support among carers; 2) faster/earlier dementia diagnosis and support; 3) more frequent respite breaks, appropriate for carers' needs; 4) specialized dementia care; 5) dementia awareness and training for health and social care professionals; 6) continuity of care; and 7) more transparent and easier care pathways and legal systems.

Conclusion: This study identified a limited number of interventions focused on improving health-promoting self-care in carers of people with dementia. Useful information was collected from research experts, carers and other stakeholders to inform for future research and support for carers. This presentation will show further study findings, will discuss these in relation to current policies and will provide recommendations for care and future research.





POSTER ABSTRACTS

Carer support and training - Poster

P03-015

PROVIDING ONLINE SUPPORT FOR FAMILY CARERS OF PEOPLE WITH DEMENTIA AT THE END OF LIFE

Nathan Davies*; Jenny Hopwood; Nina Walker; Steve Iliffe; Kate Walters and Greta Rait, Research Department of Primary Care and Population Health, University College London, London, United Kingdom

Abstract:

Objective: Caring for someone with dementia can be challenging and families and friends are faced with a great deal of uncertainty as well as emotional and physical strain which can be heightened at the end of life. This study aimed to: 1) understand what family carers find particularly challenging towards the end of life; 2) explore their views of receiving support for these challenges online, 3) use this information to develop a prototype support website for family carers.

Method: A qualitative methodology was adopted using three phases:

Phase 1) Qualitative study: semi-structured interviews with 20 older (over 65 years) current and former family carers of people with dementia

Phase 2) Intervention development: synthesis of evidence from interviews and systematic review within the research team and consulting expert research development group

Phase 3) User testing: semi-structured interviews with 11 older current and former family carers of people with dementia for user testing of prototype website.

Thematic analysis methods were used throughout all phases to analyse and synthesise findings.

Result: Carers discussed two areas of challenges and need for support: 1) informational; and 2) social/emotional support.

Discussions of informational support included the need for honesty, in particular around the realities of caring and its impact on life, and discussions around taboo topics of incontinence and sexuality. Carers were concerned with what to expect towards the end of life and planning for death. However, they also wanted practical information about providing care including what to do when someone stops eating or drinking.

The prototype addressed these challenges and concerns through sections including planning for end of life; what to expect towards the end of life; and communicating with the person with dementia in later stages.

Discussions of a lack of social and emotional support often were described from a context of shrinking social networks. They described a new identity with different relationship dynamics and roles. Carers described the potential role of the internet in meeting these social and emotional support needs. The prototype included information of looking after yourself (feelings of guilt, stress), but also interactive functions of finding other local carers in the area to meet face to face, chat and support within a private section of the website and finally signposting of local services.

User testing with families provided a positive response to the prototype and ideas for ongoing iteration. Many carers had positive views of receiving support online and the prototype illustrated how this may be feasible, however they still valued the mix of technology with human interaction.

Conclusion: This study has developed a prototype which appears acceptable and positively received by carers. However, further development of the website will need to encompass a combination of online (virtual) support and face to face human interaction.



Carer support and training - Poster

P03-017

CARERS AND EMPLOYMENT; UN-TAPPING THE POTENTIAL

Ms. Amanda J McCarren*, Tide, Glasgow, United Kingdom

Abstract:

1 in 7 workers in Scotland provide care for someone; unpaid carers of people with dementia make up 44% of the dementia workforce, 66% of these carers say that they do not get the support they need. 12% of carers employed have had to reduce their hours of work and 9% have to give up work altogether because of their caring responsibilities.

Carers provide £11.6 billion worth of unpaid care to people with dementia in the UK. They are the biggest workforce and without them the NHS and social care system would collapse. Yet they often struggle maintain their working life or face barriers when looking to return to employment

Through engagement with carers on the **tide** network, two main strands have been highlighted within the subject of employment. Firstly many carers are combining their caring role with maintaining a full time job and family life. They find that without support and flexibility from their employers this combination becomes extremely stressful and leads to a myriad of issues not least affecting their careers but also having a detrimental affect on their caring role. Secondly there are a large number of carers whose caring role has diminished or ceased altogether and they find themselves wanting to return to employment but having lost confidence, they don't know where to start or how to translate the skills and experiences honed in their caring role onto an application or into an interview setting.

This presentation will illustrate how **tide** supported our members through a narrative approach to highlight these issues on a number of platforms in Scotland It will show how **tide** worked collaboratively with our members to offer organisations and employers new, creative solutions and alternative paths to supporting carers within the workplace

The presentation will also showcase a new module devised for our development programme called **"Embracing Life"**. This was co-produced alongside a **tide** network member, who had direct experience of these issues

The module is underpinned by the coaching **GROW** model (**G**oal setting, **R**eality checking, **O**pportunities and **W**illingness), and is informed by the twelve principles of 'The Work We Were Born To Do^[1]. In the words of Nick Williams (1999) **"The way out is within, there is a sacred place within us where wisdom and clarity dwell"** (p.9).

With the current recruitment crisis in the care sector, we believe that (former carers) are a significant untapped asset in their local communities and local employment economy

Whilst there are a number of carer support services available across Scotland that provide practical, financial and legal support and advice to carers whilst in their caring roles, there is **no** focus on former carers, enabling them to realise the transferrable skills and knowledge gained from their unique experience and caring and enabling them to use these positively to re-engage with life

^[1] Williams N (1999) The Work We Were Borne To Do – Finding the work you love, love the work you do. Element Books Limited Shaftesbury, Dorset



POSTER ABSTRACTS

Carer support and training - Poster

P03-018

CREATING A POSITIVE APPROACH® TO CARE FOR FAMILY CARE PARTNERS

Rosanne M Burke Mrs., Keji Consulting, Dartmouth, NS, Canada

Abstract:

The number of families affected by dementia is growing. Most people living with dementia continue to live at home with the support of family members. Most people, however, are not prepared for the caregiving role and do not have the necessary knowledge or skills to care for a person living with dementia. More support is needed for family care partners. This workshop will increase knowledge of dementia and brain changes and will teach communication techniques to help overcome common communication challenges. Learners will have the opportunity to practice Positive Approach® to Care “care partnering” techniques including Positive Physical Approach™ (PPA™) and Hand-Under-Hand® (HuH®). These skills enable care partners to shift from simply “dealing with the behaviors” to creating a positive and caring environment. The learners will develop better observational skills to recognize and intervene effectively when behavioral situations occur, will develop new skills related to approach, cueing, and ability to connect with a person living with dementia. The workshop emphasizes the value of matching helping behaviors to the person’s needs and abilities to promote a sense of control and self-direction. It is based on Teepa Snow’s Positive Approach to Care techniques and philosophy.

This workshop is for individuals who want to:

- Increase their awareness of dementia and brain changes
- Learn communication techniques to help care for a family member living with dementia
- Learn how to change their approach towards the person living with dementia

By the end of the workshop, learners will be able to:

1. Describe changes in vision that impact a person’s ability to respond to communication and interaction initiated by another person.
2. Discuss each step of the PPA™ and the rationale.
3. Discuss purpose and value of using Hand-Under- Hand®.
4. Describe ways in which you can make a person being cared for feel productive and valued.



POSTER ABSTRACTS

Carer support and training - Poster

P03-019

“IT WAS THE HARDEST DAY OF OUR LIVES”; SUPPORTING RESIDENTS WITH DEMENTIA AND THEIR FAMILIES IN THEIR MOVE TO A LONG-TERM CARE HOME

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Abstract:

Most people with dementia typically move to a long-term care home late in the disease, when decisions may be hard for them to make. In fact, at least 67% of seniors living in a long-term care home have a diagnosis of Alzheimer's disease and/or other dementia. As the disease progresses, families are usually the ones that have to decide when, and if, it is appropriate for the person with dementia to move to a long-term care home. Yet, making the decision to move to a long-term care home may be one of the most difficult decisions families will ever have to make. However, it may also be one that is necessary, both for the caregiver's well-being and that of the person they are caring for.

In 2016, the Alzheimer Society of Canada created a resource to help support individuals with dementia and their families through the many stages of moving to a long-term care home. The resource has four pieces. Each piece of the resource was developed to help families and people with dementia plan ahead and consider strategies to help when considering the move, preparing for the move, handling moving day and adjusting after the move. Things to consider and user-friendly checklists are included in all four pieces.

Staff in long-term care homes can play a pivotal role in making the move-in day and adjustment period less traumatic for families. Information about challenges faced by a person with dementia and their family when moving to a long-term care home will be provided along with tips and strategies from caregivers' perspectives on how to make the transition into long-term care less traumatic. Participants will become aware of two types of resources created by the Alzheimer Society of Canada: to support individuals with dementia and their families in their move to a long-term care home, and to support the development of strong relationships with families during the adjustment phase to a long-term care home.





POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-001

CROSS CULTURAL ASSESSMENT OF ANXIETY IN OLDER ADULTS: PITFALLS AND PERILS OF RESEARCH WHEN THE RESULTS CANNOT BE TAKEN AT FACE VALUE

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Abstract:

Late-life anxiety is an under-researched area, possibly because symptoms of anxiety are generally considered to decline with age. Higher rates of anxiety are found in people with mild cognitive impairment, which may reflect the transition stage between normal cognition and dementia, although the nature of the relationship between anxiety and cognitive impairment remains unclear. In Australia, the prevalence of anxiety in older adults is unknown, due to lack of data from prevalence studies and of targeted tools to measure the dimensions of anxiety in older adults. The 20-item Geriatric Anxiety Inventory (GAI) was developed in Australia to address that gap and provides a measure anxiety in older adults, with a 5-item short form also available. Since its development, the GAI has been validated for people living in the community and residential care facilities as well as for people attending memory clinics and other settings. According to the authors, the GAI has been translated into more than 20 languages and is used in over 20 countries around the world.

As part of a wider dementia prevalence study in Indigenous people living in the Torres Strait in Far North Queensland, our research team used the GAI and GAI short form to assess late life anxiety in participants. As older Indigenous Australians are at increased risk of cognitive impairment including a fivefold increased risk of dementia we hypothesised that we would find higher rates of anxiety symptoms in the Torres Strait. 90% of the participants spoke English as a primary or co-primary language and the questionnaire was originally administered in English with the help of a local interpreter who clarified questions and translated into local languages as needed.

The results we obtained on the GAI ran contrary to the research evidence regarding rates of anxiety in older adults suggesting that administering the tool in English with translations was not sufficient. We had some difficulty explaining some of the expressions e.g. "butterflies in the stomach" that suggested this is not how anxiety is described or experienced in the Torres Strait.

This paper will outline some of the detail of the study highlighting the pitfalls and perils of research where the main lesson learned was that you cannot take results at face value when the tool has not been properly trialled. Our next step is to translate and back translate the tool into the three main Torres Strait languages and trial the tool again to explore the dimensions of anxiety in this population.



POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-002

COMMUNITY ENGAGEMENT AS A MEANS TO MAXIMISE RESEARCH ENGAGEMENT WITH INDIGENOUS POPULATIONS: LESSONS LEARNED ALONG THE WAY

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Abstract:

Indigenous people have lived in Australia for at least 40,000 years and have a long history of engaging in research using their own distinctive cultures, knowledge, and world view (1). Historically, non-Indigenous researchers were known for using Indigenous knowledge for their own career advancement rather than sharing their findings to benefit the communities involved. Even well intentioned researchers failed to recognise how the prevailing social and political values of their time influenced their interpretation of the research findings, often to the detriment of participants involved (1). For such reasons, research and researchers continue to be regarded cautiously by Indigenous communities. However, as Indigenous Australians experience more complex health issues, significantly higher rates of chronic disease and lower life expectancy than the general population (2) and significantly a dementia prevalence rate of more than five times higher than the Australian population (3), addressing such health inequities remains an important area of research.

To overcome such issues, non-Indigenous researchers need to focus on building relationships within Indigenous communities and involve community participation in all stages of their projects (1). This ensures that research is relevant to the community needs; facilitates the translation of knowledge into practice; is culturally appropriate; and recognises the cultural diversity of the communities involved. Developing effective collaborative relationships between researchers and the community is the cornerstone of community engagement but may seem daunting to new researchers unsure of how to engage in community engagement.

The aim of this paper is to outline some strategies for meaningful community engagement utilised by a small group of researchers who have been collaborating for many years with local Indigenous communities to determine dementia prevalence rates in specific Indigenous communities; to identify associated risk and protective factors for dementia; and to promote healthy ageing. Insights from the research team's own experience will be presented to provide practical examples of community engagement and consultation. Pitfalls and lessons learned will also be shared.

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POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-003

CULTURAL CONSTRUCTION OF ALZHEIMER'S DISEASE AND RELATED DISORDERS AMONG ALASKA NATIVES AND PROVIDERS IN RURAL AND URBAN ALASKA

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Abstract:

Objective: The proportion of the Alaska Native population aged 65+ is projected to increase between 2015 and 2045, from 7-12%, and health care providers are ill-prepared to meet the demand of Alzheimer's Disease and related disorders (ADRD). There is an increasing urgency to better understand Alaska Native views of ADRD.

Method: Guided by Kleinman's explanatory model of illness, a qualitative, research design was utilized to gather data on experiences with ADRD. 21 interviews with Alaska Native caregivers and 12 interviews with health care providers in rural and urban communities were completed. Using Nvivo qualitative software, thematic analysis was used to obtain cultural perspectives on ADRD. This study was approved by the University and regional and local tribal review boards.

Result: Many Alaska Natives view ADRD as a natural part of the aging process, resulting in not always seeking medical care. Caregivers challenges included family denial, exhaustion and isolation, and family distancing themselves due to fear and limited understanding of ADRD. Caregiving benefits included spending time with older adult, learning family history, and sharing experiences with other caregivers. Healthcare provider challenges included rigidity of the healthcare system, no research on Alaska Natives, limited health literacy, limited community resources, and no knowledge of Alaska Native views of ADRD.

Conclusion: Understanding the cultural underpinnings of ADRD provides insight into how health care providers can integrate cultural beliefs into treatment to improve the processes of care that may mitigate the impact of ADRD on individuals and families. Culturally-responsive education and training about ADRD is crucial to connecting Alaska Natives with ADRD to care that can assist them in aging more comfortably.





POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-004

TOWARDS HEALTH EQUITY: ELIMINATING RACIAL AND ETHNIC DISPARITIES AMONG HISPANICS LIVING WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIA'S IN THE UNITED STATES THROUGH A COMMUNITY ENGAGEMENT MODEL**Maria Ordonez**^{*}, Nursing, Louis & Anne Green Memory & Wellness Center , Boca Raton, FL**Abstract:**

As the population ages, the number of people diagnosed with Alzheimer's disease and related dementias (ADRD) continues to rise. The psychosocial burden of ADRD is substantial, affecting individuals, families, and society as a whole. The current health care system is not equipped to adequately meet the needs of an aging population, which has led to the emergence of new models of care. Many dementia-specific programs fail to fill this gap, as they are not nurtured by caring science. Moreover, individuals living with ADRD and their caregivers in minority communities are often underserved when trying to access dementia specific care and supportive services. Immediate family members within the Hispanic community provide the majority of the care as informal and unpaid caregivers. Literature review shows depression, stress, low self-efficacy, and knowledge deficit about the Behavioral and Psychological Symptoms of Dementia (BPSD) as some of the effects from prolonged caregiving. Culturally tailored support groups for informal Hispanic caregivers have demonstrated beneficial outcomes.

This session will discuss *Bridging the Gap: Providing Specialized Dementia Care and Supportive Services through Community Partnerships* (BGDCS-CP). An overview of the challenges and successes and specific experiences targeting the Hispanic population will be presented. The BGDCS-CP innovative nurse-led dementia specific health care model was developed as an Alzheimer's Disease Initiative – Specialized Supportive Services grantee program focused on providing in-home health services by geriatric nurse practitioners to previously unserved or underserved populations, and culturally tailored support and educational groups for informal and formal Hispanic caregivers. Program objectives included measuring its effect on caregiver self-efficacy with the Revised Caregiving Self-Efficacy Scale (RCSES), perceived stress with the Perceived Stress Scale (PSS-10), depression with the Patient Health Questionnaire (PHQ-9), and knowledge regarding BPSD with a pre and posttest.

Preliminary data show statistically significant improvements in depression, increased knowledge of BPSD among participants attending support groups, including culturally tailored sessions. Over 90% of participants reported great program satisfaction. Caregiver interventions resulted in reduced feelings of depression, anxiety, stress, isolation, and perceived burden; increased perceived competence to fill caregiver role and challenges. Also, increased community awareness as measured by recording the number of participants in training and educational sessions.

This program represents a profound step towards health equity by eliminating racial and ethnic disparities among Hispanics living with Alzheimer's disease and related dementias in the United States through a community engagement model. This model recognizes nurses leading, collaborating, and transforming health care environments and responding to the call and responsibility to be innovative leaders, charting the course for the rest of the nation in our approach to provide specialized person-centered clinical care and support for unserved or underserved individuals with ADRD and their caregivers. This program has served and can continue to serve as a model to improve health outcomes as well as the nation's health recognizing the significant role of diversity in dementia specific care: "One size does not fit all."



POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-005

DEMENTIA IN AOTEAROA: MULTICULTURAL VIEWS ON THE LIVED EXPERIENCE OF DEMENTIA IN NEW ZEALAND.

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Abstract:

Objective: There are reported to be over 60,000 people living with dementia in NZ (at a cost of \$1700 million) and this number is projected to triple by 2050. These figures are extrapolated from other countries' statistics as there has never been an NZ dementia prevalence study. Local memory clinic data from the South Auckland suggest that dementia is more common amongst Māori and Pacific peoples, and that dementia is highly stigmatized in Asian communities. Very little is known about the lived experience of dementia in the major NZ ethnic groups. Culturally appropriate and responsive services for dementia prevention, diagnosis, and management for the NZ population can only be developed if the true extent of dementia is fully described both overall and in major ethnic groups. The objective of our research programme is to understand the lived experience of dementia in the major communities living in NZ.

Method: We used qualitative research methods including focus groups and individual interviews with people with dementia, their care partners and healthcare professionals from four different communities (Māori, Pacific, Chinese and Indian) to identify common and ethnic-specific themes that describe their lived experience of dementia. We worked in partnership with different community organisations to identify potential participants for our research. We interviewed individuals and held focus groups in the following languages: English, Te Reo Māori, Samoan, Tongan, Cantonese, Mandarin and Hindi. The recorded data were analysed using a grounded theory approach to identify themes that describe the lived experience of dementia in different communities. Where possible data were analysed by bilingual researchers to avoid material being distorted by translation into English.

Result: The background and general methods of the research will be presented in this session. The findings from four of the communities (Maori, Samoan, Tongan, and Chinese) will be described in the next four presentations (see abstracts Dudley-1567, Cheung-1600, Fa'alau-1598, Kautoke-1599).

Conclusion: The logistics and challenges of conducting multicultural research in several different languages will be discussed. Our aim is to share experiences and reduce stigma for people and their families living with dementia from all major NZ ethnic groups. We will do this by raising public awareness and encouraging the exchange of ideas about this common disease. We will use our findings to inform the development of a national prevalence study of dementia and culturally appropriate services in NZ.



POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-006

ENGAGING NZ ASIANS IN DEMENTIA CARE AND RESEARCH: THE CLINICIANS' PERSPECTIVES

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Abstract:

Objective: Asian people comprise the third largest ethnic group (11.1%) in NZ. Dementia is often difficult to diagnose in people whose first language is not English. The objective of this study is to explore the views of healthcare professionals (HCPs) who have experience and/or an interest in working with Asian people on dementia care and research.

Methods: The first stage involved four focus groups of a convenience sample of HCPs. Each focus group had 6 to 8 participants discussing three broad questions: (1) What dementia research is important to NZ Asian people? (2) Where do Asian communities get their information about dementia? (3) Which is the best avenue to engage the Asian community? The focus groups were video-taped. Four researchers independently searched for themes in the data and agreed on the final themes following an iterative process. The second stage involved a focus group of 11 Asian HCPs with the aim of clarifying and refining the main themes.

Results: 30 HCPs (female 63.3%; Chinese 63.3%, European 20.0%, Korean 10.0%, Indian 6.7%) participated in four focus groups in the first stage. Their professional backgrounds included nursing (23.3%), social work (20.0%), medical (10.0%) and occupational therapy (10.0%). Three main themes emerged: (1) the lack of availability of culturally appropriate clinical pathways and support services; (2) education for healthcare professionals, older Asians and their families; (3) culturally specific communication and dissemination of education.

Conclusions: Engaging Asians in dementia care and research requires a whole-systems inter-generational approach starting from the community and the provision of cultural appropriate services.





POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-007

LEVERAGING TRUST: EXPLORING THE POTENTIAL FOR PARTNERSHIPS BETWEEN DEMENTIA SERVICE AND IMMIGRANT-SERVING AGENCIES TO IMPROVE ACCESS TO DEMENTIA INFORMATION AND SUPPORTS FOR KOREAN- AND PUNJABI-SPEAKING COMMUNITIES IN CANADA

Sharon D Koehn^{*1}; Neil Drummond Dr²; Morgan Donahue Ms.¹; Min-ah Cho Ms¹ and Fabio Feldman Dr³, (1) Gerontology, Simon Fraser University, Vancouver, BC, Canada, (2) Family Medicine, University of Alberta, Edmonton, AB, Canada, (3) Patient Safety and Injury Prevention, Fraser Health, Surrey, BC, Canada

Abstract:

Objective: A regional health authority and Alzheimer Society chapter in British Columbia have valuable resources on dementia and other health and social supports, but they do not know how to adapt their policy and practice tools to address the complex problems of access for immigrant older adults and their families. Staff in immigrant-serving agencies typically understand the multiple barriers and facilitators to access for these populations and are better positioned to gain the trust of immigrant older adults. Our research explores if and how partnerships between such mainstream dementia services and immigrant-serving agencies can increase the accessibility of dementia information and supports for immigrant older adults.

Method: Semi-structured interviews were conducted with 20 staff members (11 dementia service staff, including physicians, nurses, managers, coordinators and front-line staff; 9 managers or front-line immigrant-serving staff working with Punjabi or Korean communities). The Candidacy Framework facilitated a nuanced understanding of the multidimensional construct of access. The notion of trust was also viewed as an overarching prerequisite.

Result: Different dementia service agencies are familiar with each other but know little about the services offered by immigrant-serving agencies. Dementia service agencies have limited multilingual/cultural capacity whereas immigrant-serving agency staff know little about the characteristics of dementia, dementia service agency resources (e.g. First Link®), and referral procedures. While dementia service staff focused on language as a barrier for Punjabi and Korean older adults accessing their services, immigrant-serving staff identified other barriers to access. These included perceptions that services in the home country were more advanced and/or accessible, the stigmatized nature of dementia, and for some, a lack of social support needed to bridge knowledge and cultural gaps. Our participants suggested that collaboration between immigrant-serving and dementia service agency staff could increase the potential for connecting immigrant older adults with dementia support and care services in the community.

Conclusion: Fostering knowledge exchange and building trust between dementia service and immigrant-serving agencies holds great potential for increasing access to information and supports for immigrant older adults. By partnering with immigrant-serving agencies, dementia service agencies can expand their linguistic and cultural capacity. This requires a thoughtful investment in education, distribution of resources, and communication in order to build and maintain trust. End users in need of dementia services need to trust service providers if they are to engage with available education and supports. Fostering opportunities to integrate alternative narratives on aging, health and illness into Western-dominated health care services can foster that trust. Partnerships between mainstream dementia services and immigrant serving agencies have proven successful in increasing the accessibility of these specialized resources, in part because they understand the multiple barriers and facilitators to access for these populations, but also because they are seen as more trustworthy.



POSTER ABSTRACTS

Diverse populations - inclusion and equality - Poster

P04-009

THE LIVED EXPERIENCE OF DEMENTIA IN NZ TONGAN COMMUNITIES

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Abstract:

Background: Pacific people make up the fourth largest ethnic (7%) group in New Zealand, and Tongans are the third largest ethnic group amongst Pacific. Despite being an overall young population, there has been a steady rise in the elderly Tongan population with a concurrent increased risk of developing dementia. Literature regarding dementia in Tongans is non-existent, but NZ memory service data suggest that Pacific people are presenting with dementia at a younger age and with more advanced symptoms than NZ Europeans.

Objective: To identify and interview NZ Tongan families about their lived experiences of dementia from a Tongan worldview.

Method: Collaborating with two not for profit local organizations we identified ten dyads of Tongan elders with mild dementia and their partners and also five caregivers of people with severe dementia. Participants were offered talanoa sessions in Tongan and English depending on their preference. Tongan research methodologies together with a constructivist grounded theory methodology were used to explore and analyse the data. NVIVO was also used to assist in analysing the data.

Result: The background and general methods of the research will be described in session Cullum-1415. This presentation will focus on the unique socio-cultural understanding of Tongan concepts and themes regarding the lived experience of dementia.

Conclusion: The findings of this research will help tailor health policy and practice required for the specific management of dementia in Tongans living in New Zealand.





POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-001

EARLY INSIGHTS FROM A NEW PROGRAM: THE MULTIMODAL INTERGENERATIONAL SOCIAL CONTACT INTERVENTION (MISCI)

Dr. Phaedra Bell¹, Global Brain Health Institute, Atlantic Fellows for Equity in Brain Health, UCSF, San Francisco; **Natasha Boissier**, UCSF Memory and Aging Center, San Francisco; **Kristine Yaffe**, UCSF, San Francisco and **Brian Lawlor**, Global Brain Health Institute, Dublin, Ireland

Abstract:

Objectives Loneliness and social isolation are key risk factors for developing dementia, functional decline, and a host of chronic and terminal illnesses as we age.¹⁻² It has been estimated that, if scaled globally, interventions targeting these and other modifiable factors could prevent up to 44 million cases of dementia over the next 20 years.²⁻³

The **Multimodal Intergenerational Social Contact Intervention (MISCI)** is a new, evidence-based social intervention aimed at decreasing loneliness in older adults. This project is taking place in San Francisco through the [Atlantic Fellowship for Equity in Brain Health](#) at the [Global Brain Health Institute](#), based at the [UCSF Memory and Aging Center](#) and [Trinity College, Dublin](#).

Methods MISCI pairs undergraduate and postgraduate students with socially isolated older adults to build a relationship through a creative project. It features

- **Pre-program training and pairing.** In pre-program training, students learn about brain health, communication techniques, and how to minimize bias and maximize productive collaboration. Students and elders are matched according to creative interests and primary language.
- **Creative project development.** Students and elders co-create a project together during six 60-minute meetings over three months. They share their creative projects at a final showcase.
- **Program evaluation and improvement.** Impact on loneliness, mood, and age-based bias in both groups are measured pre-, mid-, and post-program quantitatively using validated scales, as are students' attitudes toward dementia. Interviews, focus groups, and student journal observations provide qualitative data to inform program development.

Results Our intervention is currently at Stages 0-1 of the National Institutes on Aging Stage Model for Behavioral Intervention Development. Eight undergraduates, one pre-health postgraduate student, and one medical student will work with six older adults screened for social isolation in San Francisco in a developmental study in early 2018. We hope to gain early insights to inform an expansion of the program for further study.

Conclusion When the program expands, we can investigate whether college students can mitigate loneliness and improve mood among older adults with effects similar to those achieved by peers in Ireland in a 2014 study.⁶ Secondly, we will study how the creative project impacts intergenerational relationships and secondary effects on mood and ageism among student volunteers.

For references and more information, see <https://tinyurl.com/MISCIwiki>.



P05-002

EFFECTIVENESS OF COGNITIVE STIMULATION THERAPY WITH CULTURAL ADAPTATIONS FOR VETERANS WITH DEMENTIA

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Abstract:

Objective: The purposes of this study include: (1) to develop a cognitive stimulation therapy for Taiwanese veterans (CST-TVA) protocol; (2) to investigate the effectiveness of CST-TVA on cognitive function, depression, as well as behavioral and psychological symptoms of senior veterans living with dementia.

Method: The study was developed in two stages. Stage one, based on literature and an unstructured interviews, the CST-TVA protocol was developed. Stage two, a pre-experimental with single-blind trial was adopted with twenty-five veterans with dementia from three Veterans Homes in Northern Taiwan. Participants were randomly assigned to the cognitive stimulation therapy for Taiwanese veterans (CST-TVA), which followed by a twice-weekly for seven weeks protocol, while the control group with routine activities. Primary outcomes were the levels of cognitive function [Alzheimer's Disease Assessment Scale-Cognition (ADAS-Cog)], depression status [Cornell Scale for Depression in Dementia (CSDD)] and neuropsychiatric symptoms [Neuropsychiatric Inventory Questionnaire (NPI-Q)]. Outcomes were assessed pre-test and post-test after the intervention. Nonparametric Statistics were used to compare mean-change scores between pre-test and post-test for the effectiveness of CST-TVA program.

Result: ADAS-Cog, CSDD, and NPI-Q severity and distress levels were significantly ($p < .05$) better in CST-TVA but not in the control group. The sub-domain of memory and language ($p < .005$) in cognitive function, the sub-domain of mood-related signs ($p < .05$) in CSDD, and also sub-domain of depression/dysphoria ($p < .05$) in NPI-Q were also improved in CST-TVA participants.

Conclusion: The CST-TVA rather than common activities, even in a short (7 weeks) intervention, was more effectiveness for improving cognitive function, depression status, and neuropsychiatric symptoms. A cognitive stimulation therapy with cultural adaptations with dementia is important. Future studies need large samples.

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Psychosocial interventions - Poster

P05-004

DEVELOPMENT OF A PSYCHOSOCIAL INTERVENTION TO SUPPORT COMMUNITY-DWELLING PEOPLE WITH DEMENTIA WITH CHANGED BEHAVIOURS AND THEIR FAMILY CARERS

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Abstract:

Objective: *BACKGROUND*

People with dementia develop behaviour that can be challenging, e.g. dependent or aggressive behaviour. These behaviours have negative consequences for the quality of life of the person with dementia, their family carer (dyad) and their relationship. Most psychosocial interventions that have been developed for coping with changed behaviour are not tailored to the needs, abilities and background of the dyads. Thus, there is a lack of individualized psychosocial interventions. Furthermore, a multidisciplinary approach is found to be important for coping with changed behaviour, although this is not often integrated in interventions for people with dementia living at home.

AIM

The objective of this project was to develop and test an evidence-based individualized intervention to treat changed behaviour among people with dementia living in the community with the help of a family carer. The intervention can also aim at improving the way family carers cope with or perceive the behaviour of their loved one.

Method: *INTERVENTION*

The intervention is a tailored intervention with a multidisciplinary approach for people with dementia living at home and their family carers. It consists of six steps and involves, e.g. making a detailed description and profound analysis of the behaviour, involving the physician and psychologist and formulating and evaluating a plan for coping with the behaviour. The dementia case manager (CM) is responsible for carrying out the intervention and monitoring its effects. The multidisciplinary nature of the intervention lies in the fact that a physician, and especially a psychologist are closely involved.

PILOT TEST

The intervention was pilot tested three times by participating CMs and dyads to gain insight in its usability and acceptability. Firstly, the intervention was used by CMs ($N=3$) who kept a log. Dyads and CMs were interviewed. After adjustments we decided to observe CMs that carried out the intervention to gain more in-depth insight in how CMs use the intervention and in dyad's experiences in two rounds (two times $N=2$). Thereafter, final adaptations were made to the intervention manual.

Result: Important considerations after pilot testing the intervention were: CMs struggled to make a profound analysis of the behaviour; CMs requested simplification of the intervention manual and the feasibility of the multidisciplinary approach varied significantly between regions. Further, CMs underlined the need for an individualized intervention. They were satisfied with the approach and the outcomes it yielded. They perceived the multidisciplinary approach to be very useful. Family carers had positive experiences with the intervention. They felt listened to and appreciated the time that was taken to thoroughly consider their situation. Adjustments to the intervention during the pilot tests were aimed at, e.g. intensifying the involvement of the psychologist and simplifying the intervention manual.



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Conclusion: Preliminary results on the feasibility and acceptability of the intervention are promising. The results suggest that the intervention is a useful method for CMs when changing behaviour occurs at home. Next steps are: broadly distribute the intervention manual and improve CMs' training in the intervention. Further, to support local collaborating professionals to implement the method and accompanying multidisciplinary approach as part of the National Dementia Plan.





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Psychosocial interventions - Poster

P05-005

THE DEVELOPMENT OF THE PROMOTING INDEPENDENCE IN DEMENTIA (PRIDE) INTERVENTION TO ENHANCE INDEPENDENCE IN DEMENTIA

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Abstract:

Objective: Receipt of support soon after a diagnosis may facilitate better adjustment and ongoing management of dementia. Dementia adviser services are a key aspect of post-diagnostic care in the United Kingdom. The aim of the Promoting Independence in Dementia (PRIDE) study is to develop a post-diagnostic psychosocial intervention to help keep people living as well and as independently as possible in the community by; (1) promoting social inclusion, (2) harnessing the support and encouragement of the person with dementia's social network, and (3) engagement in stimulating cognitive, physical and social activities.

Method: The Medical Research Council (MRC) framework for the development and evaluation of complex interventions guided the development of the PRIDE intervention. Firstly, research literature, early interventions (e.g. self-management), and theory (e.g. social learning theory, self-efficacy theory, social network theory, selection, optimisation & compensation model) were examined to form the basis of the intervention. Work by the study team on the benefits of exercise, physical health, and internet and technology use informed the content of the intervention. Data from the English Longitudinal Study of Aging examining cognition, vision and hearing and loneliness was also considered. Group, interview, and email consultations with persons with dementia, their supporters and dementia advisors were conducted in through which the intervention and the resultant manual were refined.

Result: Thirty-two consultees including people with dementia, carers, dementia advisers, older people, and staff provided feedback on the first draft of the PRIDE intervention and manual. A number of minor amendments were made in response. Thirty four dyads trialled the manual, which was delivered by dementia advisors across up to three sessions. Fidelity data was gathered, and focus groups and interviews were conducted after completion of the intervention.

Conclusion: The PRIDE social intervention for delivery by DAs is in the process of development. Consultations with stakeholders have played a key role in shaping the intervention and accompanying manual. Fidelity data and qualitative analysis is currently being carried out. This may lead to further revision of the intervention and manual in preparation for evaluation in a full-scale randomised trial. We look forward to presenting the final results and the intervention in due course.



P05-006

THE EFFECTIVENESS OF A COMMUNITY/HOME-BASED COGNITIVE REHABILITATION PROGRAM FOR PEOPLE LIVING WITH DEMENTIA

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Abstract:

Objectives: Grouped programs provided for persons living with dementia are less involved with the simultaneous establishment of a home-based cognitively-sound environment. The present study thus based on the approach of compensation for lost functions in neuropsychological rehabilitation to enhance the literacy of people with dementia and their family members in terms of cognitive environment settings, as well as the use of external aids and environmental supports to solve the problems caused by their functional disabilities.

Methods: This grouped program leading by clinical and counseling psychologists, and members mainly included people with dementia (Clinical Dementia Rating<2) and their families. A total of 4 persons living with dementia and 2 caregivers was involved in the group. This program runs once a week for 2 hours per session over 7 weeks in a community-based care center. The program consists of understanding the relationship between cognition and life, the impact of dementia on life and establishing a cognitively-sound environment. Most importantly, we combined grouped program with individual home visits, for developing tailored cognitive environmental settings to each family with dementia. The Holistic Supportive Relationship Scale, mainly concerned with the supportive environment provided by clinicians, was used to evaluate the effectiveness of the working alliance and the effectiveness of this program.

Results and Conclusions: The results showed that the social interactions of people with dementia increased when using contextual modeling, implementation and activities in group. Moreover, a procedure of home visits transformed learned skills in the grouped program into practices in real life, which can significantly enhance the experiences of supportive environment of families with dementia.





POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-007

PILOT TESTING THE EFFECTS OF SOMATOSENSORY GAME ON COMMUNITY-DWELL ELDERLY

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Abstract:

Objective: The aims of this study was to compare the effects of 8-week somatosensory game and accompany in increasing attention, verbal fluency and memory of community-dwell elderly.

Method: Twelve community-dwell older people with mild cognitive impairment were chosen from two adult daycare centers. Two adult daycare centers were randomly assigned into a somatosensory game group and the accompany group (control group). Fourteen adolescents from a junior high school near adult daycare centers were assigned into two adult daycare centers. Prior to contact older people, all adolescents were briefed characteristics of older people with mild cognitive impairment. Adolescents who were assigned into somatosensory game group were taught how to play the game. Eight older people in the somatosensory game were received adolescents one-to-one somatosensory game 50 minutes per time, once per week, for 8 sessions; while four older people accompany group were received adolescents one-to-one accompany 50 minutes per time, once per week, for 8 sessions. Data were collected at pre-test and at post intervention. Data was analyzed using descriptive analysis and paired t-test.

Result: Mean age in somatosensory game group was 78.14 (SD5.15), while 81.75 (SD3.95) was in accompany group. Majority was female, widowhood and six-year education in both groups. After 8-week intervention, despite that there were increase of attention and verbal fluency in somatosensory game groups, no significance was found. However, recite in order and total scores of recite and reverse recite in order memory between pre- and post-test in somatosensory game groups were significant (pair t-test=-2.731, p=.034; pair t-test=-.5284, p=.002). Recite in order memory between pre- and post-test in the accompany was significant. Mean differences of attention, verbal fluency, recite in order memory and total score of recite in order and reverse recite in order memory between both groups were not significant.

Conclusion: Based on our result of pilot study, both groups revealed effect in improving recite in order memory. The effect in memory in somatosensory game group seems better in accompany group. However, even though attention and verbal fluency score increased after intervention, there is no significant. It might be from small sample size. It is recommended to conduct large scale clinical trial to confirm the effect of somatosensory game in intergenerational program in the future.



POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-008

VALUE-BASED MENTAL HEALTHCARE: A “COMMUNITY-BASED GROUPED COGNITIVE REHABILITATION FOR PEOPLE LIVING WITH DEMENTIA”

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Abstract:

Objectives: Since the grouped programs for people living with dementia usually are not involved with establishing “supportive environment”, we planned a grouped program of cognitive rehabilitation for people living with dementia to provide a person-centered mental healthcare. The present study thus aims to build a friendly environment for preventing and alleviating cognitive disabilities and emotional symptoms.

Method: Twenty people in this group completed 12 two-hour sessions once a week. The programs of this group included cognitive training, social interaction training and consulting led by five psychologists. The Outcome Rating Scale (ORS) and Session Rating Scale (SRS) in each session were evaluated, and the Holistic Supportive Relationship Scale (HSRS) was also assessed.

Results and Conclusion: The results showed that the given program could help people living with dementia to be more involved in social interactions. Meanwhile, the sense of “trust”, “safety”, “belongingness”, “responsibility”, and “well-beings” of persons living with dementia and their family members was also enhanced.





POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-009

EFFECTS OF PSYCHOSOCIAL INTERVENTIONS ON QUALITY OF LIFE IN ALZHEIMER'S DISEASE

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Abstract:

Alzheimer's disease (AD) continues to be a tremendous emotional and financial burden to both individuals living with AD and caretakers. It is a neurodegenerative disorder characterized by accumulation of beta-amyloid protein plaques and tangles of tau protein in the brain. Studies show that sleep disturbance, depression, and anxiety increase the risk for developing AD. Additionally, stress has been implicated in long-term anatomical changes in the brain associated with AD. As individuals age, they may become more isolated from friends and family, and more dependent on caretakers to assist with basic needs. This isolation and loss of independence may increase the risk of depression and anxiety, and predisposition for AD. Data from the Alzheimer's Association show that 5.3 million Americans have Alzheimer's, with 5.1 million aged 65 years and older. Estimates of lifetime risk for AD were, 1 in 5 for women, and 1 in 10 for men. New cases of AD are projected to be 615,000 by 2030, and 959,000 by 2050. These projections emphasize the need for expanding resources dedicated to a variety of treatment protocols. There are very few studies on ageing-related cognitive decline or dementias which include participants from multicultural backgrounds. Therefore, implementing culturally sensitive interventions in treatment protocols for patients pre-AD or with mild cognitive impairments, may reverse or delay some impairments. This study will review data on the efficacy of different psychosocial interventions in individuals of different gender and ethnic background who are living with dementia.





Psychosocial interventions - Poster

P05-010

THE INDIVIDUALIZED APPROACH IN DESIGN OF MENTAL MAPS FOR PEOPLE WITH ALZHEIMER DISEASE

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Abstract:

Since recently we started to use mental maps in psychoeducation, for early diagnosis of Alzheimer's disease (AD), cognitive training for people with dementia (PWD), problem solving situations and making treatment or caring plan. These mental maps provide a schematic display of important and useful information about AD through connected words, sentences, symbolic icons or drawings. Such valuable graphic technique improves learning and coping strategies for formal and non-formal caregivers of PWD in understanding their needs. Furthermore, we recommend the personalized approach to PWD individualized and orientated to needs of each person him/herself according to the stage of his/her disease, his/her activities, interests, life important events, BPDS problems.



POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-011

THE ART THERAPY FOR PEOPLE LIVING WITH DEMENTIA

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Abstract:

Objective: People living with dementia commonly experience behavioral and psychological symptoms (BPSD), which has negative effect on quality of life of both themselves and their care partners. Pharmacologic treatments for BPSD are usually limited in efficacy. In the absence of cure for dementia in recent year, we went through the literature on BPSD. Some studies showed that art therapies might be helpful to stabilize the mood. With art therapies, people living with dementia could be more attentive and happier. The extent of social behavior and self-esteem could also be elevated, improving BPSD. Therefore, we collaborated with the Eyeball Art Museum to conduct art therapies.



Method: We invited artists and nurses to develop a 12-week course to teach people living with dementia how to draw. The course was held in the Eyeball Art Museum, which was full of eyeball-related artworks, stimulating imagination and inspiring the visitors. We guided people living with dementia to think about what made them depressed or agitated and which memories reminded them of happiness. They tried to paint these scenes. Through the course, they used multiple cognitive functions, such as attention, logistics process, which could lower the rate of cognitive function decline. They also shared with others in the tips of how to draw best and helped each other to cope with bottlenecks of painting. By interactions with others, the extent of social behavior and self-esteem could be elevated.

We utilized the Clock drawing test (CLOX1), which is non-invasive and less influenced by education and culture, to evaluate the efficacy of the intervention. The statistical analysis was made with SPSS 20.0.

Result: 13 participants attended the course. The result showed that the average scores before and after the intervention were 9.7 and 11.30 respectively (Table 1., Mann-Whitney U test, $P > 0.05$). It indicated that the intervention could improve the cognitive function. However, the result did not reach the statistical significance. Our result was similar to Kim's study which focused on artistic therapies for MCI (Kim, 2014). Kim's result showed that artistic therapies cannot improve the cognitive function, but can indeed stabilize the mood. We speculated that our intervention could stabilize the mood and enhance the extent of social behavior and self-esteem, which caused the difference between the average scores, not caused by the improvement of the cognitive function.

Table 1. Intervention of art therapies before and after the analysis

Art therapy	Before	After	Mann-Whitney U	Z(p)
CLOX1 average	9.7 (SD 2.45)	11.30 (SD 2.63)	42.000	-.634(.579)

Conclusion: Art therapies could stabilize the mood and enhance the extent of social behavior and self-esteem, providing ways to improve well-being and quality of life of people living with dementia and care partners.



POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-012

THE POTENTIAL ROLE OF DRAMA THERAPY FOR THE PREVENTION AND DELAY OF ALZHEIMER'S DISEASE AND DEMENTIA FOR AT-RISK INDIVIDUALS

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Abstract:

As the world's population ages, the number of people living with Alzheimer's disease (AD) and dementia is expected to increase globally to 75 million by 2030. With no effective medical or pharmacological treatment for AD and dementia, incorporating alternative approaches to prevention would be prudent (Winblad et al., 2016). The objective of this research is to introduce drama therapy as a psychosocial approach for the prevention and delay of AD and to describe the research protocol to be implemented.

Drama therapy (DT) is a therapeutic method using drama/theatre techniques to help individuals achieve their therapeutic goals (NADTA, 2018). This approach regards the participant as a multifaceted "individual" living in the here-and-now; e.g. physical, psychological, emotional, social, and spiritual being, thus, promoting a person-centre approach to behavioural research. DT provides distancing techniques so the individual can safely explore psychological and physical concerns affecting their behaviour and overall health. These adaptive methods can include preventative factors for AD and dementia: exercise, cognitive stimulation, social interaction and networking; and can address some of the risk factors such as depression, stress, and anxiety.

The research protocol to be used in this study is based on the Obesity-Related Behavioural Intervention Trials (ORBIT) model. This approach is flexible and iterative in nature and based on testing the drivers of behavioural factors for chronic disease. The ORBIT protocol includes: a Pre-Clinical Phase which includes identifying the drivers of the behavioural factors, the design of the behavioural treatment (Phase I), the testing of the treatment package (Phase II), the development of the efficacy trial (Phase III), and the effectiveness trial (Phase IV) (Bacon et al., 2015, Czajkowski et al., 2015).

The Pre-Clinical Phase has identified exercise, cognitive stimulation, social activity and networking, stress, anxiety and depression as the drivers of the modifiable behavioural factors. The design of the Phase I behavioural treatment is underway.

Frydman (2016) presents a theoretical model that shows the connection between DT and cognitive neuropsychology. He suggests role method in DT has a direct counterpart to executive functioning in neuropsychology. In DT the client uses their physical abilities to express themselves in the here-and-now to communicate emotion. Embodiment is used in DT as a way for the client to use their body to become more physically, mentally and emotionally aware, in their process of change and personal growth in their future behaviour (Jones, 2011). DT by its very nature is physical and can provide the exercise component required in the biomedical approach (Jones, 2011). Drama therapy, when implemented as group therapy, enriches the social dimension of individuals, reduces isolation and enhances self-worth. The social situation created by drama therapy group work taps into their creativity and reconnects them to others as well as gaining a deeper appreciation of self (Reinstein, 2002). Drama therapy interventions provide the tools to cope with stress and anxiety that can enhance AD prevention. Drama therapy provides a model of aesthetic distancing and expanding roles that can aid in addressing anxiety and stress issues (Landy, 1994).

In conclusion, DT can provide an alternative approach to addressing the behavioural factors that can contribute to the prevention and delay of Alzheimer's disease.



POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-013

REGIONAL ADAPTATION OF THE MEETING CENTRE SUPPORT PROGRAMME: THE EXPERIENCE IN SOUTHERN ITALY

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Abstract:

Objective: The Meeting Center Support Programme (MCSP) was developed and positively evaluated in the Netherlands, based on the theoretical Coping and Adaptation Model. The main aspects are: timely and integrated support, collaboration with dementia care organizations, emotional support, social participation, leisure activities involving Pwd and caregivers (Droes et al.,). The MCSP was successfully implemented in other 3 European countries (IT, PL, UK) (Van Mierlo et al, 2017) within the Meetingdem project (that is a JPND research project). This study presents the results of the implementation of the MCSP in southern Italy, especially focusing on what concerns the analysis of facilitators and barriers for setting up meeting centers in southern regions.

Method: Concerning the methodology, it was applied the one we developed during the Meetingdem project (Droes et al., 2017). Six organizations from three Italian southern regions, who are involved in dementia care, attended a training course about MCSP. Please note that in Italy healthcare system has always been public and still falls under a regional competence. At the end of the course, our 25 participants discussed about what barriers and facilitators they could find in their local realities. Through a checklist and guided by a skilled facilitator and projects expert, the participants were asked to rate individually each item of the checklist first and recognize them as a facilitator or as a barrier then. Furthermore, this work was made at different levels: from a micro to a macro- level, passing through a meso- level. During a final plenary session, all participants discussed about it and were also asked to suggest solutions suitable for their contexts and care organizations.

Result: During its preparatory stage, the participants indicated as facilitators the following items: the scientific evidence of MCSP, the enthusiasm of involved organizations, a Public Relation strategy, informative meetings, the local needs, the supports of national Alzheimer associations. Other items were seen both as barriers and facilitators: being attuned to the local care and support offer; the volunteers' involvement, other organizations' collaboration, the initiative group's role, the financial support and the management support. The location was identified as a barrier, because it needed an adequate and specific space. The participants reported also solutions to be adopted in order to overcome barriers or to turn some barriers into facilitators. The focus mainly was on the need for intensified efforts to involve other care and welfare organizations, a health policy, to raise awareness among stakeholders and citizens but also enlighten Pwd, their caregivers and professionals about MCSP.

Conclusion: The result outlines that the facilitators and barriers can be different among regions and only the development of specific and different solutions can be seen as a premise for the success of this new model.



P05-014

THE IMPACT OF VIRTUAL MEMORY PALACES ON WELL-BEING IN DEMENTIA

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Abstract:

Objectives: Dementia, and Alzheimer's Disease in particular, is the problem of the future in health care. Dementia is hard for the person living with it, but even more burdensome for his/her environment. The conversational dialogue between them seems to decline.

The primary objective is to examine whether the addition of (augmented) reality to communication strategies can reconnect subjects in the early phase of Alzheimer's Disease (AD) with their caregivers and family members.

The secondary objective includes a follow-up on recall and recognition of familiar faces. As well as a follow up on quality of life of subjects in the early phase of AD and their significant others.

Method: We have developed a mobile application (MemoryHome) which allows caregivers to construct virtual scale models of the residential settings these individuals with early AD presently are living in. These models function as *memory palaces* in which photos of significant others are connected to the architectural, spatial environment. It is a visual-audio-guide through a well-known environment and subjects in the early phase of AD can make this walk together with a caregiver or a family member.

Results: Our intervention is non-pharmacological, rather inexpensive, patient-friendly, unconventional and easy to combine with regular treatment of Alzheimer's disease. Data was collected in two different environments: in homecare and residential settings. Results showed a modest but positive effect of MemoryHome on quality of life, connectedness between caregivers and their family members and the absence of feelings of geriatric depression.

Conclusion: Our mobile application is a convenient instrument to reinforce the dialogue that seemed to diminish between patients and their environment.

Furthermore the application will allow participants to independently improve the recall and recognition of familiar faces, as a positive side effect.

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P05-016

THE INFORMAL CAREGIVERS OF PERSONS WITH DEMENTIA EXPERIENCES IN THE CARING PROCESS IN ESTONIA

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Abstract:

Objective: In the Estonia there are no sufficient various services and does not yet developed network which are support the informal caregivers, such as memory clinics, counselling, support groups etc for PwD and their relatives as others European countries. In 2016 the Estonian NGO “Life with Dementia” was founded. One of the organization's goals is to develop empowerment activities for informal caregivers of older family members with dementia. To better understand the current situation, the best way would be to obtain deeper understanding of the variety of challenges faced by an informal caregiver. This would also help to understand how the perceived burden of care is associated with social support and/or the ability to cope.

The aim of the study was to describe and analyze the experiences and needs of informal caregivers regarding the caring process with their relatives with dementia. The research questions were: How do informal caregivers of older people with dementia experience their role as a caregiver and how that affects their life?

Methods: The study carries out an action research, which target is developed empowerment activities for informal caregivers of person with dementia. The Action Research is planed consist of 30 months, from October 2016 to January 2019.

The presented study is the first step in the action research cycle which is based on narrative approach. Sample was purposive and used also snowball sampling. During from February to May in 2017 narratives were carried out with 16 caregivers from different Estonian counties. Interview lengths ranged from 1:35 to 2:20 hours (mean 1:45). The interview was recorded, made notes during the interview and transcription by the first author. The transcribed material is included in total on 225 pages. Interviews were thematically analyzed using inductive data coding.

Results: The study showed that informal caregivers have difficulties finding information about dementia and they lack knowledges how appropriately take care of their family members. They perceived role conflicts, mental and physical strain and negative changes in their lifestyle.

Conclusion: The informal caregivers need more counseling and psycho-emotional support, information, recommendation and different support services regarding persons with dementia. Social and health care politicians should focus on the development of health and social welfare coherence and develop supportive services and activities for the person with dementia and their family members. Providing support to informal caregivers is therefore essential to promote their well-being and prevent caregiver burden.



POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-017

THE ROSEMARY DIARY: A USEFUL TOOL FOR PEOPLE WITH DEMENTIA

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Abstract:

Objective: the Rosemary diary is an useful tool for older person with cognitive impairment to build the track of time and monitor the daily tasks and activities; the diary has be planned to be use without istructions, but simply using intuition with icons and pictures that accompany simple questions. The first part makes references to the traditional ROT (a part of CST actually)- Reality Orientation Therapy, while the second part collects the activities of daily life. The aim of the study is to determine if this tool strengthens cognitive performance and autonomy as compared to traditional model of home care.

Method: the case series consisted of 87 PWD (30 M, 57F9; mean age: 80 \pm 74 years) divided into a study Group (n°71) submitted to a Rosmarine project (use of agenda lasting one hour/day for 6 day per week for one month) and into a control Group (n° 16) with an usual care. At the start (T0) and the end (T1) of the study time, the 2 groups were screened for cognitive performance with MMSE, activities of daily living with Barthel index and the affective status by GDS- short version. The statistical analysis was conducted by SPSS-21.

Result: for both groups significant improvements was found for depression (SG-GDS: $t=5.36$, $p<0.001$; CG-GDS: $t=2.25$, $p<0.05$) and functional parameters (SG-ADL: $t=7.85$; $p<0.001$; CG-ADL: $t=2.37$, $p<0.05$), whereas only the study Group had a significant improvement in MMSE scores ($t=7.31$, $p<0.001$).

Conclusion: these preliminary results confirmed tha a simple tool such as Rosemary diary had positive effects on cognitive functions as temporal and spatial orientation and enviromental behavior; they are important to explain functioning in ADL. Using this tool the cognitive stimulton may not be limited to improve orientation and memory, but also interact to improve skills in ADL to promote and maintain autonomy. The Rosemary diary is a simple and economic tool, a *pair of memory glasses* that helps to maintain, organize and consolidate cognitive functions for every daily activity but these observations need more accurate studies conducted on a large sample of people with cognitive impairment.



POSTER ABSTRACTS

Psychosocial interventions - Poster

P05-018

LIFE REVIEW FOR AN OLDER ADULT WITH MIDDLE STAGE DEMENTIA IN COMMUNITY RESIDENTS

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Abstract:

Objective: The purpose of this study was to develop a life review (LR) for an older adult with middle-stage dementia and describe the themes of their life review through personality, the interaction with other people, and preference by a deep understanding .

Method: 1. Subject :Mrs. B, aged 80 had middle-stage dementia (CDR2) for several years. She communicated verbally.

2. Implementation: LR was conducted four times. Each session lasted 60 minutes or more. She reminisced about her past through her photographs selected as 'childhood', 'adolescence', 'adulthood' and 'mature'.

3. Data collection method: The researcher recorded the four sessions and documented the observations the emotional expressions such as speech tone, facial expressions, changes in behavior, emotions, and embarrassment.

4. Editing a memory book: In addition to the photographs and the words spoken, the researcher created a hand-made ' memory book'.

5. Analysis: The verbal and non-verbal content of an older adult was written verbatim, and the described semantic contents were interpreted and qualitatively analyzed.

Result: The sessions conversations were analyzed into six categories, which unified the sessions:

- a** To talk about 'at that time' with the background of the times;
- b** Proud to work supporting the family;
- c** Reflected on nurturing my children;
- d** Nurture interactions with people through work;
- e** My current situation;
- f** To thank you for exchanges with the son's family.

These categories demonstrated the changes that occurred through the life review process. The photographs provided the stimuli for recall and were associated with pleasurable feelings. Repeating the life review sessions yielded a treasure trove of recollections, stimulating pleasure and building new meaningful narratives about her life. It was thought that Mrs. B's importance of her family and the expression of her feelings about 'at that time' and the feelings of 'I feel right now' were due to the talk about her work and were nurturing to her mental state.

Conclusion: Despite the immediate memory decline, this woman was able to stay focused enough to narrate specific pictures from the past. Life review presents an important opportunity to talk about childhood to present.



P05-019

A SYSTEMATIC REVIEW AND META-ANALYSIS OF NONPHARMACOLOGICAL INTERVENTIONS FOR MODERATE TO SEVERE DEMENTIA

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Abstract:

Objective: People with dementia (PWD) are rapidly increasing all over the globe. Given that there is no cure for dementia yet, nonpharmacological interventions (NPINT) play a key role in the management of PWD. However, the efficacy of NPINT is still in debates, particularly in people with moderate to severe dementia (PWMSD). We conducted a systematic review and meta-analyses on NPINT for PWMSD to investigate the effects of NPINT on cognition, activities of daily living (ADL), behavioral and psychological symptoms of dementia (BPSD) of PWMSD.

Method: We conducted the literature search on Cochrane CENTRAL, EMBASE, Medline, CINAHL, PsycINFO, KoreaMED, KMBASE, and KISS. We also reviewed the references of pertinent studies. We conducted meta-analyses on randomized controlled trials (RCT). We used the generic inverse variance method with a fixed-effects model to calculate the standardized mean difference (SMD). We carried out narrative reviews on the non-randomized controlled trials and before-after studies. We registered this systematic review protocol to the PROSPERO (CRD42017058020).

Result:

Ten RCT met the inclusion criteria for meta-analyses. The NPINT including 2 multi-component treatments, 1 light therapy, 1 music therapy, and 1 physical treatment were effective in improving ADL (SMD = 0.28, 95% CI = 0.11 ~ 0.45). NPINT including 2 multi-component interventions, 1 light therapy, and 1 massage treatment were effective in reducing depression (SMD = -0.44, 95% CI = -0.70 ~ -0.19). However, NPINT were not effective in reducing agitation (SMD = -0.14, 95% CI = -0.21 ~ 0.49), anxiety (SMD = 0.01, 95% CI = -0.45 ~ 0.48) and overall BPSD (SMD = -0.16, 95% CI = -0.39 ~ 0.06). In subgroup analyses, the music therapy was effective in reducing BPSD (SMD = -0.52, 95% CI = -0.90 ~ -0.13).

Conclusion: In PWMSD, NPINT were found to be effective in improving ADL and reducing depression. However, the number of studies that can be included in our meta-analyses was very limited.



POSTER ABSTRACTS

Younger onset dementia - Poster

P06-001

YOUNGER ONSET DEMENTIA COGNITIVE PROGRAM (ESTEEM): ASIA'S EXPERIENCE AND ITS BENEFIT

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Abstract:

Objective: Engaging in cognitive stimulation program and staying social active after diagnosing of dementia has been advocated in mild to moderate stage of the condition. Studies has suggested that such engagement have beneficial effects on memory and thinking process, as well as positive effects for wellbeing for both person with dementia and their caregivers. In Singapore, the prevalence of young onset dementia (YOD) is increasing and yet there is no structure program that can support YOD and their caregiver after diagnoses is given. Hence, evaluating the first structure program for this unique group.

Method: ESTEEM program (Early STimulation Exercise EMotional) is a collaborative work between National Neuroscience Institute (NNI) and Alzheimer's Disease Association (ADA), catering for YOD and is modelled after Family of Wisdom concept since 2014. Person with YOD and their caregivers will be engaged in a once a week, 3 hours program run by both team with the 3 mainstay focuses on Physical Activities, Cognitive Stimulation and Emotional Well-being. The highlight of the program Caregivers will be group together for an hour of huddle session while their love ones will be engaged in planned cognitive stimulating activities.

Result: 32 person with YOD had joined ESTEEM program along with their caregivers since 2014. 80% of the group was mainly English language speaking and more than half of them are male. Person with YOD's activities include: preparing a meal from scratch, baking cookies and cakes from scratch, art and craft, and cognitive stimulating games and activities. Most of them verbalised some degree of difficulties in completing these tasks but with the assistance and support from caregivers and staff, the challenges are minimised and had enjoyed these tasks. Person with YOD were also invited to be a part of the planning phase of the activities.

On the other hand, caregivers had underwent planned activities on Art therapy (6 sessions weekly) where caregivers express their caregiving journey and emotion through art , mindfulness (6 sessions weekly) where caregivers were empowered and learned some self-help stress-relieving strategies. Smell-a-memory (10 sessions, weekly) was a session that conducted with person with YOD. All caregivers constructively reported that they had enjoyed these sessions and is able to express and ventilate their emotion openly and effectively in a protected environment. Both person with dementia and the caregivers had reported that they had enjoyed the 3 hours session weekly.

Conclusion: This is heartening and indeed a good work to be able to implement the first structure program that supports YOD and their caregivers after diagnosis. Person with YOD would require a different type of support and services as compared with person with late onset dementia. ESTEEM program will be reviewed for longer hours and vocation.



Younger onset dementia - Poster

P06-002

PREDICTIVE VALUES OF CLINICAL DEMENTIA RATING - MEMORY DOMAIN AND SHORT BLESSED TEST FOR PUERTO RICAN FAMILIES WITH EARLY ONSET FAMILIAL ALZHEIMER'S DISEASE

Alexandra Rivera¹; Jorge M Acevedo Canabal¹; Dr. Ivonne Z Jiménez-Velázquez²; Ginette González Ramírez³; José Nieves¹; Arturo Pérez¹; Mariela M Rivera Agosto¹; Nathalie Rivera¹; Aleyda Maldonado¹ and María Rodríguez¹, (1)University of Puerto Rico School of Medicine, San Juan, Puerto Rico, (2)Department of Medicine, University of Puerto Rico School of Medicine, San Juan, Puerto Rico, (3)University of Puerto Rico - Río Piedras Campus, San Juan, Puerto Rico

Abstract:

Objective: Early Onset Familial Alzheimer's Disease (EOFAD) is associated to mutations of PSEN1, PSEN2, and APP genes. EOFAD is a rare condition, accounting for less than 1% of Alzheimer's Disease (AD) cases. Inheritance of pathogenic mutations occurs in an autosomal dominant pattern; the offspring of patients have a 50% risk of inheriting the disease. The clinical presentation of EOFAD is similar to that of sporadic AD, distinguished only by onset before 65 years of age. The age of onset of EOFAD varies widely, even among members of the same family. Since there is no cure, genetic testing to identify carrier-status is not routinely advised. However, due to the increased risk that members of families with EOAD have, these could benefit from screening tests that identify early symptoms. The Short Blessed Test (SBT) and the Clinical Dementia Rating-Memory Domain (CDR-M) are screening tools used to identify cognitive impairment. This study describes these screening methods' accuracy in diagnosing dementia due to EOFAD in Puerto Rico.

Method: A sample of 206 participants ≤ 65 years of age with positive family history of EOAD were administered the SBT and CDR-M for cognitive function evaluation. Positive results were defined as a score ≥ 10 for the SBT, and a score ≥ 1 for the CDR-M. All tests were scored by physicians. Results were correlated to previous EOFAD diagnosis, and data analysis was performed to determine the Positive Predictive Value (PPV), Negative Predictive Value (NPV), Sensitivity, and Specificity of both screening tools.

Result: The prevalence of previously diagnosed EOAD in our studied group was 15% (n=31).

Results for Short Blessed Test are summarized in Table 1. Out of the 58(28.2%) participants with a positive SBT, 40(69%) had not been previously diagnosed. Of the remaining 148 participants with negative SBT results, 13(8.8%) had been previously diagnosed with EOFAD.

Table 1. Short Blessed Test diagnostic accuracy for EOFAD.

	EOAD Diagnosis (+)	EOAD Diagnosis (-)	total		
SBT (+)	18	40	58	31%	PPV
SBT (-)	13	135	148	91.2%	NPV
total	31	175	206		
	58.1%	77.1%			
	Sensitivity	Specificity			

Results for CDR-M are summarized in Table 2. From the 35 participants with a positive CDR-M test results, twenty(57%) had not been previously diagnosed with EOFAD. Among those with a negative result (n=171), sixteen(9.4%) had been previously diagnosed with the condition.



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Table 2. Clinical Dementia Rating - Memory Domain diagnostic accuracy for EOFAD.

	EOAD Diagnosis (+)	EOAD Diagnosis (-)	total		
CDR-M (+)	15	20	35	42.9%	PPV
CDR-M (-)	16	155	171	90.6%	NPV
total	31	175	206		
	48.4%	88.6%			
	Sensitivity	Specificity			

Conclusion: In our study, the SBT and CDR-M screening tests were found to have limited sensitivity and positive predictive value for diagnosing EOFAD. These results do not necessarily represent a problem with the instruments' diagnostic usefulness. Possible explanations for these findings include underdiagnosis of condition and underreporting during interview, among others. Results for the tests' specificity were better, ranging between 77.1% (SBT) and 88.6% (CDR-M), and both tests had a negative predictive value >90%. Based on these findings, we can conclude that a negative result in these tests may provide some reassurance at the time evaluation to patients with family history of EOFAD. However, further studies to make sure this high-risk population is being adequately served are needed.



POSTER ABSTRACTS

Younger onset dementia - Poster

P06-003

OUR LIFE WITH YOUNGER ONSET DEMENTIA

Mr. Hiroyuki Kobayashi, Toyama-city, Japan

Abstract:

My wife was diagnosed with younger onset Alzheimer's disease when she was 51 years old in March 2014 (table-1).

Before diagnoses, she was very busy as a high school teacher, housewife and mother for three children. She became quiet and expressionless year by year. I was upset when she was in a bad mood and we often quarreled. She was diagnosed with depression in 2013 and later she was diagnosed with Alzheimer's disease in 2014.

Just after diagnoses, she was confused and I was very disappointed. I tried to help her but my mental condition got worse and worse when I thought about my family's future, finally I was diagnosed with depression. I drove my car to send and fetch my wife to and from her school every day, sometimes I was very sleepy by the medicine for dementia. I was called by her boss every month and she told me what kind of mistakes my wife did while looking at the notebook. Actually, it was one of my worst experience in my life. One day, the other boss of my wife told me that I had to decide my wife's resignation someday and suggested to take sick leave from the next year. She and I wanted to work more as a teacher, but we gave up to continue. One year after her diagnoses, she started her sick leave in 2015.

It is said that if a person with dementia is left alone at home and watching TV all day long, the disease progresses. My wife was accepted as a volunteer by a day service center for elder (sometimes with dementia) and disabled people, luckily. She helps staffs there every week day washing dishes and so on. She enjoys the word there, feels productive and I am happy for her. We had good time joining ADI international conference in Australia and Asia Pacific conference in New Zealand. Even though she forgets the memory of those travels, I will remember for two of us instead. Living with dementia is not convenient but not unhappy.

Table-1 Major events of mi wife

Year	Age	Events
1962	0	born in 28th May
1985	22	started carrier as a high school Mathematics teacher
1991	28	got married
2013	51	made many mistakes at school, diagnosed with depression
2014	51	diagnosed with younger onset Alzheimer's disease
2015	52	started sick leave and working at day service center as a volunteer
2016	53	started receiving disability pension
2018	55	early retirement on the 31st March





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Younger onset dementia - Poster

P06-004

DEVELOPING DEMENTIA: THE EXISTENTIAL EXPERIENCE OF QUALITY OF LIFE WITH YOUNG-ONSET DEMENTIA– A LONGITUDINAL CASE STUDY

Kirsten Thorsen, Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tonsberg, Norway; Norwegian Social Research (NOVA), Oslo Metropolitan University, Oslo, Norway; **Aud Johannessen**, Faculty of Health and Social Sciences, University College of Southeast Norway, Borre, Norway; Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tonsberg, Norway and Marcia C.N. Dourado, Centre for Alzheimer's Disease and Related Disorders, Institute of Psychiatry, Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brazil

Abstract:

Objective: Cognition and the ability to take care of daily activities and oneself gradually decline among people with dementia. Studies are scarce, especially regarding how young people with dementia (YOD) (<65 years) experience the quality of their lives with the progression of dementia. People with dementia living alone face special challenges. We therefore aimed to examine the experience of quality of life with YOD as a single person.

Method: The study presents a longitudinal case study with in-depth interviews exploring the experiences of a person with YOD. Individual interviews were conducted seven times over a period of three years from 2014 to 2017.

Result: We examined if and how seven themes concerning quality of life and well-being were fruitful for understanding the experiences of dementia in the everyday life of a single individual. The study explored needs and challenges during the development of the dementia, and how the person reacted over time, set in context. The themes significant for well-being are: identity, connectedness, security, autonomy, meaning, growth and joy.

Conclusion: The study shows how treatment, support, and services have to be individualized when the dementia develops to support identity, resources and mastering capacity, and promote Well-being.





Younger onset dementia - Poster

P06-005

SMELL-A-MEMORY THERAPY: EFFECT ON PERSONS WITH YOUNGER ONSET DEMENTIA AND THEIR CAREGIVERS

Ying Ying Chong*, Family of Wisdom Programme, Alzheimer's Disease Association, Singapore, Singapore; Lay Hoon Lim Ms, Department of Neurology, National Neuroscience Institute, Singapore, Singapore and Yong Lock Ong Dr, Family Of Wisdom Programme, Alzheimer's Disease Association, Singapore, Singapore

Abstract:

Objectives: It is known that the sense of smell plays a significant role in memory, mood and emotion. Few studies have reported the use of smells and its outcome with Persons with Younger Onset Dementia (YPWD). This project continues to explore the use of scents provided by Givaudan© (Vernier, Switzerland) as a complementary therapy. The group involved consisted of YPWD and their caregivers. It will also highlight any differences from the previous two presented projects working with Older People with Dementia (PWD).

Methods: YPWD and their caregivers known to Alzheimer's Disease Association (ADA) and National Neuroscience Institute (NNI) were invited to participate in the sessions. Smell-A-Memory (SAM) therapy was conducted weekly over ten sessions for YPWD and their caregivers. A range of scents were specially selected based on the theme set for discussion at each session for example: religion, food, festivals, occupations and homes. Any spontaneous topics brought up by participants were explored further. All responses from participants were recorded for analysis purposes.

Results: There were a total of seven YPWD (mean age: 62) and five caregivers (mean age 56) who completed the ten sessions of SAM therapy. Two salaried caregivers were excluded from participating. The group consisted of six females and one male YPWD. Five were diagnosed as mild-stage dementia and two with moderate-stage dementia. The caregivers consisted of two husbands, two daughters and a son.

From the feedback questionnaires filled by caregivers, 100% were positive about the sessions. The Quality of Life (QOL) scale showed an upward trend in the rating scores as compared to a downward trend in the previous groups with PWD of older profile. All caregivers felt that YPWD talked about subjects they do not usually talk about. This triggered memories for the caregivers themselves of earlier times. For example, one YPWD shared her memorable memories of her honeymoon and holidays triggered by using the rose scent. Another caregiver shared he can replicate the use of scents with his mother as a new home-based activity. Three of the YPWD who were known to be quiet in sessions using other activities, actively participated and talked about their past occupations. All YPWD and their caregivers expressed their wish to have more SAM therapy sessions. 100% of YPWD showed a self-rated improvement in their mood using a Visual Analogue Scale. In comparison to the previous two groups of Older PWD, the YPWD group was more interactive as it required less intervention from the facilitators.

Conclusion: The act of sharing scent experiences had engaged all in a joint activity. It illustrates scent recognition is locked together with memories of people, places, life events and feelings. SAM therapy could be suggested as one of the complementary therapies suitable for YPWD to stay engaged and to enhance their quality of life.



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Younger onset dementia - Poster

P06-006

A PLACE OF INCLUSION: A SOCIAL GROUP FOR PEOPLE WITH YOUNG ONSET DEMENTIA

Marivic Aplao^{*1}; Meghan Williams^{*2} and Paola Bresba², (1)Alzheimer Groupe Inc. (AGI), Montreal, QC, Canada, (2)Alzheimer Groupe Inc (AGI), Montreal, QC, Canada

Abstract:

Given the unique realities for those affected by Young Onset Dementia (YOD), Montreal-based Alzheimer Groupe Inc. (AGI) created the first YOD social group in the province of Quebec. Begun as a pilot program, with consultation and in partnership with the McGill University Centre for Studies in Aging in Montreal, AGI's YOD Social Group has now been operating for four years in a local community centre.

The needs, capabilities and interests of people with YOD differ from people diagnosed with dementia in their seventies, eighties and nineties. People with YOD tend to have: better physical strength and mobility, an awareness of their diagnosis and a recent history of forced retirement due to this diagnosis, often resulting in feelings of grief and/or non-productivity. Effective programming for this population needs to take these differences into account and focus on goals specific to this population. Those with YOD deserve programming that matches their capabilities and stage of life.

With the central aim to enrich the quality of life for participants, programming at AGI's YOD Social Group is designed with five core goals in mind:

- 1) Sense of belonging
- 2) Circle of support
- 3) Providing purpose
- 4) Creating normalcy
- 5) Life enrichment

Participants have the opportunity to build relationships with peers and engage in activities that are both meaningful and challenging, all within a safe environment. Participants appreciate meeting in a non-institutional environment, being outdoors, developing their artistic voices, playing sports, practicing meditation and going on excursions within the community. Moreover, they benefit from opportunities to be productive by volunteering at a local food depot.

We have identified three key criteria for participation within our program:

Participants

- 1) Must be able to engage in group programming
- 2) Exhibit no aggressive behaviours
- 3) Be independent in the washroom

Since the inception of the program there have been two main challenges: a heterogeneous group and low enrollment.

Heterogeneity results in a group with participants at various stages of the disease and with a range of diagnoses including: Alzheimer's, frontal temporal dementia, stroke, mild cognitive impairment, unidentified diagnosis and co-morbidity with psychiatric diagnosis. This inclusivity results in a range of capabilities requiring a high staff-to-client ratio requiring more resources from the organisation. However, this high ratio also enables the program to accommodate the unique needs of each person and adapt with the progression of the disease.



POSTER ABSTRACTS

AGI has identified three reasons for low enrollment: 1) lack of public awareness of the service, 2) difficulty fitting applicants into the set criteria and 3) transportation as i) most primary caregivers are unavailable to drive because they are working or in school or ii) distance between programming site and client residences, as AGI serves a large territory.

Moving forward, the organization must address these challenges, consider adapting the eligibility criteria for participation and continually assess and amend the program of the group as clients' abilities change.





POSTER ABSTRACTS

Younger onset dementia - Poster

P06-006

A PLACE OF INCLUSION: A SOCIAL GROUP FOR PEOPLE WITH YOUNG ONSET DEMENTIA

Marivic Aplao^{*1}; Meghan Williams^{*2} and Paola Bresba², (1)Alzheimer Groupe Inc. (AGI), Montreal, QC, Canada, (2)Alzheimer Groupe Inc (AGI), Montreal, QC, Canada

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Younger onset dementia - Poster

P06-007

"TREAT ME EQUALLY - TAKE ME SERIOUSLY – FACE ME NORMALLY" EXPERIENCES ABOUT LIVING WITH YOUNGER ONSET MEMORY DISEASE AND OPINIONS ABOUT THE APPROPRIATE ENCOUNTER AND TERMS

Virvatuli Ryyanen*, Alzheimer Society of Finland, Helsinki, Finland

Abstract:

Objective: The Alzheimer Society of Finland is promoting the positive attitudes and strengthening the agency of people with memory related diseases. In our work, we have faced many examples of encounters, where the person with younger onset memory disease has not been treated respectfully. This study was ordered to get a more systematic view of the phenomena. The aim was to collect experiences and views from people with younger onset memory diseases, as well as discover criteria of respectful language.

Method: The study was made as an open electronic survey in November 2017, with tools from Innolink Research. It was disseminated mainly through our and our local associations' social media channels. The target group was people with younger onset memory disease. Both multiple choice and open questions were included to the survey. The survey reached 41 people from different parts of Finland. Results presented here, are mainly based on qualitative content analysis.

Result: More than half of the respondents felt that their perspective was not sufficiently listened to during the examining and diagnosing of the memory disease. Some of respondents had experienced delayed diagnoses. They were being pushed between different healthcare units, furthermore being underrated in their opinions. Although, majority have received the help they need from the healthcare. The respondents said that memory disease has changed their lives especially in occupational and financial situations and friendships.

The respondents were asked to evaluate the appropriateness of various terms relating to memory diseases. When discussing the disease, they felt that the best terms are "neurological disease" and "memory disease". According to the study, a word "dementia" was not valued. "People with memory disease" and "people with a neurological disease" were considered to be best ways to describe a person. Terms "people with dementia", and "people suffering from dementia" felt particularly inappropriate, according the respondents. This outcome may be affected by the terminology used in Finland: the commonly used term is "memory disease" instead of "dementia".

Respondents especially want to be treated and encountered equally. Advices for how to encounter a person with memory diseases were collected under two lists: Don't act like this and Act this way. Examples from the don't-list are: Don't ignore, patronize, talk over, raise your voice, get flustered or make a scene if I can't remember something. The act like this -list included, for example, following instructions: Act normally and naturally, treat equally and with respect, talk appropriately. The respondents also asked others to be accepting, appreciative, positively supporting, respecting person's independence, when encountering them.

Conclusion: Based on the survey, over half of the respondents were not able to maintain a strong agency while dealing with the memory disease. When encountering people with memory disease, the keys to success are listening, taking them serious and respecting their own will. Instead of underrating attitudes towards them, people hope for equal, appreciative and normal encounters. As one example, according to the study, the memory diseases should be represented as neurological diseases.

The Alzheimer's Society of Finland will utilize the outcomes of the survey to promote positive attitudes, increase memory awareness and support inclusion of people with younger onset memory diseases.



Younger onset dementia - Poster

P06-008

YOUNG-ONSET ALZHEIMER DEMENTIA: A COMPARISON OF BRAZILIAN AND NORWEGIAN CARERS' EXPERIENCES AND NEEDS FOR ASSISTANCE

Marcia C.N. Dourado¹; Jerson Laks¹; Nathalia R. S. Kimura¹; Maria A. T. Baptista¹; Maria L. Barca²; Knut Engedal³; Bodil Tveit⁴ and **Aud Johannessen**^{5,6}, (1)Center for Alzheimer's Disease and Related Disorders, Institute of Psychiatry, Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brazil, (2)Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway, (3)Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway, (4)Oslo, VID specialized University, Oslo, Norway, (5)University College of Southeast Norway, Borre, Norway, (6)Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway

Abstract:

Objective: Although Alzheimer's disease typically occurs in older people, it can also emerge in people aged younger than 65 years, often called young-onset dementia (YOD). Cultural and national aspects, including family structure and the availability of health and social resources and institutional support, as well as attitudes toward YOD, exert a significant impact on carers' burden and stress. In response, we investigated the situations, experiences, and needs for assistance of carers of persons with YOD among persons with Alzheimer's disease (YO-AD) in Brazil and Norway.

Method: We recruited a convenience sample of Brazilian ($n = 9$; 7 women) and Norwegian carers ($n = 11$; 6 women) in 2014 and 2015, respectively, and analysed data of the semi-structured interviews in light of a modified version of Grounded Theory.

Result: In both countries the narratives revealed six common themes: Motivation to become a carer, psychological and emotional impact, impact on daily activities and self-care, professional and financial impact, social impact, and need for support services. Although Norway's public health care system is more extensively developed than Brazil's, the strain of care on carers' emotional and physical health was similar. There was similarity of professional and financial impacts on the well-being of carers in both groups.

Conclusion: The infrequent differences between carers of persons with YO-AD in Brazil and Norway indicate that carers' problems seem to be similar regardless of cultural differences and public services provided.





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End of life care - Poster

P07-001

THE KEY INGREDIENTS FOR MEANINGFUL ENGAGEMENT IN DECISION-MAKING AND FUTURE CARE PLANNING FOR PEOPLE WITH DEMENTIA WHO LIVE IN THE COMMUNITY

Michelle Lai¹; **Yun-Hee Jeon**² and Heather McKenzie¹, (1)Faculty of Nursing and Midwifery, University of Sydney, Sydney, Australia, (2)Sydney Nursing School, University of Sydney, Sydney, NSW, Australia

Abstract:

Objective: Engagement of people with dementia who live in the community in decision-making and advance care planning for their future care is an area that has been little explored in the literature, particularly which ingredients mediate their engagement. Limited evidence is available on what is required for meaningful engagement, with much of the current literature focusing on the initiation of discussions about the future or the experience of discussions. Important to this process is engaging all three members of the dementia care triad: people with dementia, their family or carers, and healthcare professionals. A systematic integrative review was conducted to identify the key ingredients for meaningful engagement in the decision-making and advance care planning process as it relates to the future care of people with dementia who live in the community.

Method: This review used the PRISMA guidelines and an integrative review methodology. The Mixed Methods Appraisal Tool was used to assess study quality. The MEDLINE, PubMed, CINAHL, PsycINFO and Embase databases were searched for articles published from 2012 to 2017 that focused on people with dementia who live in the community, their family or carers, and community-based healthcare professionals.

Result: Twenty articles were included in the review and six key ingredients identified through thematic analysis: knowledge and understanding of planning for the future of people with dementia, belief in the meaning and value of planning for the future, healthcare professionals' communication skills, timing of the initial conversation, relationship quality, and orientation to the future.

Conclusion: This review identifies the six key ingredients required for triadic engagement in decision-making and advance care planning for the future care of people with dementia who live in the community. It also situates the ingredients in the complex context in which members of the triad typically find themselves in reality or practice. This includes uncertainty about the future, sensitivity towards discussing the future, and striving for a person-centred approach, all of which underpin the process of engaging with decision-making about the future. Furthermore, the findings of this review address the gap in the existing literature on the extent of, and involvement with, engaging with shared decision-making processes by all members of the triad. Overall, the findings can inform how healthcare professionals and policy-makers approach decision-making and future care planning in this context.



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End of life care - Poster

P07-002

PALLIATIVE AND END OF LIFE CARE FOR PEOPLE WITH DEMENTIA - A CROSS BORDER LEARNING

Anna Gaughan, tide/Life Story Network, Liverpool, United Kingdom and **Ms. Amanda J McCarren***, Tide, Glasgow, United Kingdom

Abstract:

In 2014 the World Health Assembly – the governing body of the World Health Organisation - passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies

The Strategic Framework for Action on Palliative and End of Life Care sets out an ambitious, but fully achievable set of commitments that the Scottish Government will work on with partners to implement and help ensure that everyone in Scotland gets the care they need when time is becoming shorter. The Strategic Framework outlines the areas where action needs to be taken to ensure that by 2021 everyone who needs palliative care will have access to it

This action is also reflected within Scotland's Third National Dementia Strategy 2017-2020 in which commitment 6 which states; **we will support significant improvements in palliative and end of life care for people with dementia**

Despite these aspirations and ambitions, research has shown that people in the late stages of dementia receive most of their healthcare from GP's or emergency services rather than from specialist health care professionals, despite them having complex needs, researchers at University College of London (UCL) have found^[1] that healthcare services are not currently tailored to the complex needs and symptoms of people with advanced dementia. Given that dementia is now the leading cause of death, they say there is urgent need to ensure an adequate standard of comfort and quality of life for patients

The presentation will powerfully illustrate the use of narrative practice 'outsider witness' process with both people living with dementia (supported by DEEP) and carers of people living with dementia (supported by **tide**). The unique use of this process enabled both groups to talk openly – often for the very first time about what good care at end of life means for both the person living with dementia and their family carers. These two groups were then brought together in a combined session with professionals, commissioners, providers and managers to share their different perspectives. From this process, a short film was co-produced, which highlights the learning and very honest conversations that occurred. The delegates will have the opportunity to view the video as part of the presentation and participate in cross border learning that can support the commitment made in Scotland by the government around palliative and end of life care.

From this short piece of work in the North of England, it has already begun to change policy and practice. The team were invited to present their work at National (England) Dementia Workforce Advisory Group and explore how to use this approach to **shift the perception of end of life care discussions from being 'difficult' to 'important'** and create an educational resource

[1] Sampson E. (2017) Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. <http://journals.sagepub.com/doi/full/10.1177/0269216317726443> accessed on 15th December 2017



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P07-003

HAND TO HEART - HOLISTIC END-OF-LIFE CARE CELEBRATING THE LIFE LED

Elizabeth Green Ms*, Care Services, Governance and International Relations,
The Salvation Army Aged Care Plus, Redfern, Australia

Abstract:

Hand to Heart outlines The Salvation Army Aged Care Plus's care model for the provision of palliative care. Based on international and national best practice, Hand to Heart provides holistic, compassionate and person-centred care during the end-of-life journey for the person and their loved ones.

Dementia is a terminal illness, but the trajectory of the disease is different from other conditions such as cancer. The life expectancy of an individual with dementia is unpredictable and the disease can progress for ten or more years. Planning for end-of-life care in the earlier stages of dementia means people living with dementia may contribute to their care planning, and be confident about the care they receive as their condition deteriorates.

When a person with dementia arrives at the end-of-life stage, advance care planning and other planning arrangements may be implemented as agreed, ensuring the person's preferences and wishes can be met. Advance care planning is a series of steps people take to help them think about and plan for their future medical care, enabling the person living with dementia to communicate decisions about wishes for their end-of-life care. Components of a palliative approach include:

- Support for dealing with symptoms of dementia and other health concerns inclusive of nutrition and hydration, confusion and other physical indicators of palliation.
- Physical, emotional and spiritual care for people living with dementia, their carers and loved ones.
- Bereavement and respite services for carers and loved ones.

Many health needs faced by people living with dementia are already present prior to the end-of-life stage. Symptoms may increase as the disease progresses, reaching very high levels during palliation.

Some of the health related needs and symptoms include:

- Recognition and support to deal with pain (often under recognised in those living with dementia).
- Nutritional needs and support.
- Infection management.
- Personal comfort.

The end-of-life stage can be a period filled with grief and a myriad of emotions associated with losing a loved one. Bereavement services, including relevant counselling and support should be promoted and available to loved ones who often provide the majority of care, and can intensify in the later stages of dementia.

The health and wellbeing of loved ones requires recognition and support in a person-centred approach and should be identified by the care home as part of their dementia care model. For example, sending of mementos, sympathy cards and a compassionate and caring approach to the room discharge should be incorporated.

This presentation aims to focus on the provision of holistic quality end-of-life care and palliation for all, but will also be inclusive of the specific needs of those living (and dying) with dementia and their loved ones. It will focus on researched best practice and provide insights for consideration by all who attend with the presentation focusing on physical, emotional and spiritual care.





POSTER ABSTRACTS

End of life care - Poster

P07-004

INVOLVEMENT IN HOSPICE CARE: AN EXAMPLE FROM THE TORBAY DEMENTIA LEADERSHIP GROUP

Claire Garley, Dementia Voice, Alzheimer's Society, Reading, United Kingdom and **Kelly Kaye**^{*}, Dementia Action Alliance, London, United Kingdom

Abstract:

In Torbay, a coastal area in the South West of England, a group of people living with dementia meet together as the Torbay Dementia Leadership group. They want to change the world for the better for people diagnosed with the condition and their families. The group is supported by Alzheimer's Society and work to make a difference in their local community. Group members have recently been working with Rowcroft Hospice; the hospice provides specialist care to over 2,000 patients and their loved ones across South Devon each year.

The Hospice initially approached the group as they wanted to make sure their facilities take into account the needs of people living with dementia, whether as patients or visitors. As a result members of the Torbay Leadership group visited the hospice, met with staff and conducted an environmental audit, drawing on their lived experience and commenting on not only the surroundings, but also the atmosphere and the staff engagement. The group was most impressed by the warmth and friendliness of the staff they met and found the visit both fascinating and reassuring in equal measure. A member of the group said, "Such a lovely group of staff whose clear focus is on the patient".

Since that initial visit the group has returned to the hospice as an expert panel at a Special Interest Group meeting. This event, entitled 'My Life with a Dementia' gave an opportunity to attendees, mainly local stakeholder clinicians, Care Home staff and volunteers, to speak to people at various stages in their diagnosis about what life is like, their hopes, aspirations, and their fears and expectations of care. One comment from an attendee illustrated the impact of the group's contribution, "I may not have had the confidence at work to have asked a lot of questions that they handled".

This poster will showcase the partnership working between the members of the Torbay Leadership Group, Alzheimer's Society and Rowcroft Hospice. It will highlight the value and importance of this partnership, as a good-practice example of involvement and engagement, and will explore the opportunities for similar initiatives to positively impact specialist service delivery at a local level. This work champions people living with dementia as experts by experience and illustrates how people with dementia do want to plan for the future and influence how their care and support can be respected. It demonstrates how, through local groups, people are enabled to influence local health and social care professionals and increase awareness and understanding of dementia.





POSTER ABSTRACTS

End of life care - Poster

P07-006

PALLIATIVE CARE IN LONG-TERM CARE FACILITY FOR RESIDENTS WITH DEMENTIA: AN ACTION RESEARCH

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Abstract:

Objective: (1) To examine what actions could be implemented by staffs that in order to promote high quality palliative care for residents with advanced dementia. (2) To evaluate what can be learned from these processes of using action research.

Method: A two-year action research.

Result: SWOT analysis was used to establish the culture fitting and practicable palliative care model for residents with advanced dementia in study long-term care facility. The facility applied strategies that involved promoting ACP program, strengthen the palliative care preparedness of care workers, increasing communication between care teams, creating a companion environment to enhance care workers' ability of palliative care during action process. The evaluation showed that the number of DNR was increasing, hospitalization rate was decreasing. Family caregivers of residents with advance dementia who join palliative care project gave positive evaluation. The care workers who participated in these action processes demonstrated increasing knowledge of end-of-life dementia care and ACP.

Conclusion: The palliative care was applied in long-term care facility that no only improved quality of care for end-of-life residents with dementia, but also inspired the care workers' enthusiasm and confidence of palliative care.





POSTER ABSTRACTS

End of life care - Poster

P07-007

DEVELOPING NEEDS-BASED CAREGIVER SUPPORTS AND PALLIATIVE CARE INTERVENTIONS FOR RAPIDLY PROGRESSING DEMENTIA'S

Dr. Alissa S Bernstein¹; Krista Lyn Harrison²; Megan Casey³; Aili Golubjatnikov³; Daniel Dohan⁴; Christine S Ritchie²; Katherine P Rankin³ and Michael D Geschwind³, (1)Global Brain Health Institute, Institute for Health Policy Studies, San Francisco, CA, (2)University of California San Francisco, San Francisco, CA, (3)Department of Neurology, University of California San Francisco, San Francisco, CA, (4)Institute for Health Policy Studies, University of California San Francisco, San Francisco, CA

Abstract:

People with rapidly progressive dementias (RPDs), such as prion diseases, including sporadic Jakob-Creutzfeldt disease (sJCD) experience steep decline in cognition and a myriad of cognitive, constitutional, and motor symptoms. Time from symptom onset to death occurs in months to a few years as compared to 8-10 years in Alzheimer's disease. Symptoms experienced by people with sJCD include cognitive symptoms such as memory loss, depression/anxiety, and hallucinations; constitutional symptoms such as weight loss, headaches, and vertigo; and motor symptoms such as parkinsonism and ataxia. As sJCD progresses, capacity to make decisions and ability to communicate is lost, requiring proxies – typically family caregivers who provide intensive care – to make decisions on behalf of the person living with sJCD. Caregivers of people with sJCD are often invisible, and palliative care decisions must be made rapidly. Yet, clinicians have minimal evidence-based guidance to offer people with sJCD and their caregivers about what types of needs and experiences they might face.

We are developing a series of mixed-methods projects with people with sJCD, their caregivers, and clinicians. We will use qualitative interviews, quantitative analyses, mapping, and stakeholder engagement to understand the depth and breadth of needs of people with sJCD and their caregivers. This population is under-recognized and has a high level of need. We have access to a database of approximately 3,000 patients with RPDs. Our goal is to build caregiver supports and palliative care interventions tailored for the specific needs of this population.

Project 1: Mapping the Dynamics of Caregiver Burden in sJCD will assess relationships among experiences of burden, connectedness, anticipatory grief, social isolation, loneliness and spatial movement (“physical activity space”) in the home, community, and resource environment amongst family caregivers of people with sJCD. Data will include qualitative and quantitative tools developed in the social and engineering sciences, specifically, interviews, observations, and mapping using Geographic Information Systems (GIS) technology to map and describe caregivers’ experiences. This study will assess assets and resilience in caregivers with low burden and social and spatial mechanisms involved in those who are especially burdened.

Project 2: Developing the Evidence for Palliative Care for sJCDs seeks to identify palliative care and end of life needs of people living with sJCD. Palliative care includes symptom and distress management, goals of care clarification, and alignment of care with values and preferences. However, the evidence for dementia-specific palliative care interventions is nascent. This project, using secondary analysis of sJCD clinical characteristics, as well as interviews with people with sJCD and their clinicians, will provide an understanding of what is required in a dementia palliative care setting. Data will provide insights into the physical, psychological, social, ethical, legal, and cultural aspects of palliative care needs, as well as barriers and facilitators to improving end of life care for this population.

Our investigations of caregiver supports and palliative care needs in sJCD will allow us to build better supports for this population. We will use this data to develop and pilot evidence-based, stakeholder-informed, caregiver and palliative care interventions in both sJCDs as well as in other dementia syndromes.



POSTER ABSTRACTS

End of life care - Poster

P07-008

ADOPTING A PALLIATIVE CARE APPROACH IN DEMENTIA IN THE COMMUNITY PSYCHOGERIATRIC PROGRAM (CPGP) IN SINGAPORE

Lay Ling Tan Dr*; Alisson Ching Ching Sim Dr; Wei Fern Ng; Felicia Chan; Pei Lin Yik and Norhayah Noor, Psychological Medicine, Changi General Hospital, Singapore, Singapore

Abstract:

Objective: CPGP is a program set up to improve the mental health of older persons who are unable to access hospital or outpatient services. Care staff undertook an investigation into their practice to explore how they could improve their home-based palliative care provision.

Method: An action research method is adopted to involve CPGP staff in processes whereby they have an opportunity to reflect on and critique their clinical practice. 6 identified members comprising nurses and resident physicians participated in a recurring helical cycle that involves problem identification, planning, taking action, collecting data, analysis and reflection and replanning. Four meetings were convened over 6 months to complete the first action cycle. Detailed meeting notes and audio recordings were made to capture the reflections and suggested strategies of the team members.

Result: This first action cycle revealed unclear understanding of the concept of 'palliative care approach'. Staff also had different views on how and when to initiate advanced care planning. Through the action group meetings, members were able to identify learning needs and source for workshops and trainers to address competency deficiencies. A checklist was also drafted by team members to assess clients' readiness to engage in end-of-life care. Analysis of the data collected during a pilot run of the checklist was positive. Staff reflected that the action research process helped them to be more confident in adopting a palliative care approach.

Conclusion: The participatory action research methodology was effective in developing strategies for facilitating staff learning and engagement in palliative care provision. The process was collaborative, flexible and circular and allowed action with change and improvement simultaneously with research and evaluation. As the strategies were generated by the staff, they were better accepted and adopted.





POSTER ABSTRACTS

End of life care - Poster

P07-009

FACTORS THAT CONTRIBUTE TO INTENSITY OF END-OF-LIFE CARE IN OLDER ADULTS WITH ADVANCED DEMENTIA IN FRANCE: A QUALITATIVE INTERVIEW STUDY

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Abstract:

Objectives: The objective of this study is to understand how French clinicians make decisions surrounding end-of-life care decisions in older adults with dementia, particularly surrounding the provision of mechanical ventilation, ICU admission, vasopressors and other life sustaining treatments (LST). In 2005, French lawmakers passed the Claeys-Leonetti Law, which prohibits futile care ("unreasonable obstinacy") and authorized withholding or withdrawing of treatments that are deemed to be futile. This policy allowed patients to refuse futile treatments, enabled physicians to withhold or withdraw LST for unconscious patients where appropriate, and provided a framework for consensus amongst the entire team. This study aims to better understand how this law, as well as local hospital culture, policies, and clinical practices influence the intensity of end-of-life care in older adults with dementia.

Methods: Semi-structured in-depth interviews were conducted with 3 physicians and 1 nurse to date, with additional interviews planned for 16 physicians, nurses, and allied health professionals in general medicine, emergency medicine, and intensive care medicine at two hospitals in Paris this Spring. Participants were purposively sampled by seniority and profession/specialty to provide a wide range of perspectives and contribute to understanding emerging patterns and themes. Interviews lasted on average 60 minutes and were audio-taped and transcribed. Transcripts are being analyzed and using thematic analysis with an interpretive approach.

Results: Although neither old age nor the presence of mild to moderate dementia were considered an absolute exclusion criteria for admission to the ICU, a diagnosis or the presence of clinical features of advanced dementia were considered an absolute contraindication for ICU admission and LST. Instead, clinicians encouraged a focus on comfort and palliation. Decisions took into account patient preferences, especially in the rare cases that patients had an advance directive. In cases where patient preferences are not known, a family's understanding of the patient's preferences may be taken into account but physicians make the final decision and family perspectives on patient preferences were not determinative. Furthermore, family members' own preferences were not considered a very important component in decision-making. Decisions to withhold or withdraw LST are achieved through consensus of the entire interdisciplinary team including physicians, nurses, and at times psychologists, social workers, and other allied health professionals. Meetings to decide upon termination of LSTs (une réunion de Limitation et Arrêt des Thérapeutiques Actives (LATA)) were an important part of the process and can be called by any member of the team. Participants report that treatment decisions generally do not proceed until every member of the team is either in agreement or understanding.

Conclusion: Since the passage of the 2005 Claeys-Leonetti Law, ICU decision-making practices at two hospitals in Paris have adapted procedures that provide time and space to achieve consensus amongst the entire interdisciplinary team. These procedures appear to effectively encourage consensus and ethical decision-making to mitigate burdensome ICU treatments in older adults with dementia. More research is needed to determine whether this consensus also exist between clinicians, patient, and family.



POSTER ABSTRACTS

End of life care - Poster

P07-010

A QUALITATIVE ANALYSIS OF ADVANCE CARE PLANNING IN HOSPICE PATIENTS WITH DEMENTIA: “IF THEY’VE NOT DONE IT, THEY CAN’T DO IT.”

Krista Lyn Harrison*;Theresa A Allison;Nicole Thompson;Rebecca Sudore and Christine S Ritchie, University of California San Francisco, San Francisco, CA

Abstract:

Objective: In the United States, 16.5% hospice beneficiaries carry a principal diagnosis of dementia, and more have comorbid cognitive impairment affecting their decision-making capacity. The communicative difficulties associated with dementia often require the use of a proxy decision maker to complete advance care planning (ACP). We designed this multi-site, multi-stakeholder study to explore professionals’ understanding of advance care planning and to identify possible needs for people with dementia

Method: We conducted in-depth interviews with clinicians, leaders, and quality improvement staff members at four non-profit hospices across the US. Study design was informed by an interdisciplinary advisory group of hospice volunteers and professionals. We used qualitative framework analysis (combining inductive and deductive approaches) and coded data in NVivo14.

Result: Of 51 participants, 61% were clinicians, 25% leaders, and 14% quality improvement staff. Despite expertise about hospice services, there was broad discrepancy in the definition of ACP. Participants discussed ACP as narrowly as code status or as broadly as any discussion involving values, plans or preferences. Nevertheless, four themes emerged. (1) Participants estimated that a minority of new admissions with dementia had engaged in ACP prior to referral. Likelihood of having engaged in ACP or completed advanced directives was perceived to be much higher among people in nursing home compared to those receiving care at home. (2) Participants discussed the complexity of proxy decision-making regardless of whether the patient had engaged in ACP. This included discrepancies in ideas of decision-making capacity and timing of proxy involvement. In some cases, people with dementia receiving care at facilities become wards of the state with legal guardians to make decisions, because their family members had died. (3) Even in hospice, people with dementia continue to receive more invasive interventions like feeding tubes because families “don’t want their parents to die” or do not have a prior understanding of the patient’s wishes.

Conclusion: Two key features stand out among participating hospice organizations. First, even among this group of trained professionals, there is no consensus about the activities that constitute advance care planning. Second, advance care planning is conspicuously absent for many of the hospice referrals who carry a diagnosis of dementia, particularly those receiving hospice outside of nursing homes. To provide patient-centered end-of-life care to people with dementia, conversations about advance care planning must begin long before hospice admission, perhaps at the onset of mild cognitive impairment and before the loss of decision-making capacity.



P08-001

THE EVERYDAY ATTORNEY PROJECT – PROMOTING THE RIGHTS OF PEOPLE WITH MEMORY RELATED DISEASES BY STRENGTHENING LEGAL KNOWLEDGE AT LOCAL NGOS

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Abstract:

The challenge: Lack of legal knowledge

Basic legal knowledge is essential for an individual to be able to benefit of the public services he or she is entitled to. Legal knowledge is also required for a person to be able to utilize different legal arrangements, such as to make different legal documents. Simply put, a person needs to know his or her rights to be able to use them.

In Finland, a wide range of public social and health care services and benefits are provided for people with memory related diseases and their family members and carers. However, due to the complexity of the system, many are not aware of all the services and benefits available, or how to find information of them. The Finnish legislation also provides the possibility to draft pre-emptive legal documents. This way, a person can decide in advance how his or her social and health care should be arranged or on who should take care of his or her financial and personal issues in case his or her decision-making capacity was impaired. Unfortunately, many are not aware of this possibility.

The response: Improving legal knowledge at local memory organizations

In 2016, the Alzheimer Society of Finland started the Everyday Attorney project, funded by the Funding Centre for Social Welfare and Health Organisations. The three-year project spreads legal knowledge of the rights of people with memory related diseases for the employees and volunteers of the 44 local memory organizations in Finland. These NGOs have a critical role in promoting the rights of people with memory related diseases, as they offer them support and advice, advocate their rights, and arrange activities. Strengthening legal awareness at these organizations ensures that people with memory related diseases can easily get information from one place for instance if they do not know which public services to apply for or what types of pre-emptive legal documents they can draft. It also supports the organizations' advocacy work.

The project arranges two-day training sessions, held by a lawyer and a social and health care expert, for employees and volunteers of the local organizations. The participants get training on the rights of people with memory related diseases, social and health care services and public benefits, how to appeal of a decision concerning a public service or a benefit, and what types of pre-emptive legal documents a person can draft.

As the participants usually have no previous legal education, the trainings begin with an introduction to basic concepts of law and legal thinking. Everyday examples and legal cases are presented to concretize the otherwise abstract topics. Teaching methods vary from lectures to group works, and questions and discussion are always encouraged.

As the participants' legal knowledge strengthens, they have more tools to work as approachable "everyday attorneys" at their local organizations, giving advice for people with memory related diseases on their rights and on pre-emptive legal arrangements. This in turn enhances the knowledge of people with memory related diseases of their rights and how to advance them.

The progress thus far

The project arranged five trainings in 2017, and another five will be arranged in 2018. The feedback from the participants has been very positive. They have told that their knowledge of law has strengthened and that this is useful when advising people with memory related diseases. The participants have also found that the training results in enhanced legal knowledge at their local organizations.



POSTER ABSTRACTS

Rights of people with dementia - Poster

P08-003

CODE OF ETHICS IN RELATION TO PATIENTS WITH DEMENTIA

Dr. Liubov Pishchikova*, Gerontological Protection, Moscow, Russian Federation

Abstract:

Objective: International studies of aging processes are recognized by the UN and the WHO as global agenda issues, which is associated with demographic, political, socio-economic, cultural, medical and criminological problems, caused by the increasing number of age persons all over the world.

There are issues of age discrimination trend (ageism), socio-economic stratification, cruel and dismissive attitude towards elderly people, their legal and social protection insufficiency, "epidemy of dementia".

The phenomena of ageism, considering "age" as a synonym of "dementia" can lead to the violation of rights of older people, appear in general and forensic psychiatric practice, influence the reliability of diagnosis and expert assessment.

Method: Clinical and expert analysis of 235 late age patients (revealed: "non-dement" mental disorders - 45.5%, psychosis - 7.7%, dementia - 46.8%) who underwent forensic psychiatric examination in Serbsky Federal Medical Research Center for Psychiatry and Narcology in criminal and civic cases, helped us to formulate ethical principles in relation to older people:

Result: Understanding aging as a favorable regulatory process during which the evolutionary development of man continues.

- Observance of presumptions of mental health, sanity, capacity to contract and legal capacity to act.
- Inadmissibility of ageism and discrimination in all spheres and areas.
- Inadmissibility of cruel treatment, violence and neglect.
- Recognition of dementia as a disease and not as normative manifestation of aging.
- Preserving dignity and respect of a person until the last stage of dementia and his right to reside in his home.
- Inadmissibility of euthanasia.

Conclusion: To prevent abuse of the elderly a complex of legislative measure is required aimed at protection of their rights, monitoring of cases of abuse, legal, psychological, educational, medical education and assistance programs, enhancing the spiritual culture of the people, because the world's denominations do not accept disrespect against elderly individuals.



P09-001

EFFECT OF THE GROUPED EXERCISE INTERVENTION IN COMMUNITY ELDERLY WITH MILD OR MODERATE DEMENTIA

Ms. Jui-Chi Hsu¹; Jung-Cheng Yang¹; Yu-Ying Chu²; Ms. Yi-Chun Chein¹; Yi-Chen Tsai¹; Hsiao-Ting Tsai¹; Ching-Fei Lo¹ and Hsing-Yu Chen¹, (1)Phys Med & Rehabil, National Taiwan University Hospital Hsin-Chu Branch, Hsin-Chu, Taiwan, (2)Nursing, National Taiwan University Hospital Hsin-Chu Branch, Hsin-Chu, Taiwan

Abstract:

Introduction: Balance, physical activity and cognitive decline are the major problems of the person with dementia. In Taiwan, more than 90% of the people with dementia live in the community. Research has demonstrated that nursing home residents with dementia can improve their balance, strength and endurance with physical exercise. There is less evidence on the effect of grouped exercise among community elders with mild or moderate dementia.

Objective: The purpose of this study was to investigate the effect of grouped exercise intervention in community elders with mild or moderate dementia

Method: This was a clinical trial research. Nineteen community elders with mild or moderate dementia were included. There were 10 participants in an exercise group and the other 9 participants in a control group. Ten participants exercised as a group once a week for 12 weeks. The duration of exercise was 4 hours including warm up, grouped exercise and cool down. The programs of the grouped exercise included playing golf, kicking ball, passing the ball, playing frisbee, playing badminton, thera-band exercise, stretch exercise with the towel, mat exercise and outdoor activities. The control group underwent music therapy once a week for 12 weeks. The basic data included age, gender, MMSE, CDR, IADL and FIM, which were collected as they were enrolled in this research. All participants went through baseline assessment before intervention and re-assessment after 12 weeks intervention. The outcome measurements were Berg Balance Scale (BBS) and the 6-min walk test. The independent t-test was used to compare the basic data between the two groups. The two-way mixed ANOVA was used to analyze the effect of group exercise and music therapy between two groups. The significance level was set at 0.05.

Result: There was no significant difference in the basic data between the two groups. Repeated measure ANOVA showed a significant interaction for BBS ($p=0.008$) and the 6-min walk test ($p=0.014$) between the experimental group and the control group (Fig 1 & 2). In the further analysis, the experimental group significantly improved in BBS (from 47.0 ± 2.8 to 51.5 ± 1.2 ; $p < 0.001$) and 6-min walk test scores (from 308.6 ± 102.8 to 356.1 ± 64.0 ; $p = 0.045$).

Discussion: The grouped exercise effect of elders with dementia living in the community on balance and aerobic endurance in this study was similar to others. The program in the experimental group included different kinds of ball exercise, resistance exercise and outdoor activities which provided a higher intensity exercise program than the control group. Moreover, the grouped exercise provided elders with dementia the opportunity to interact with others and challenge their cognition, and there was a healthy competition during the grouped exercise.

Conclusion: Grouped exercise can improve the balance and aerobic endurance in the community elders with mild or moderate dementia.

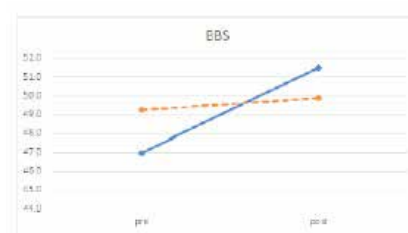


Fig 1. Pre- and post-intervention scores of Berg Balance Scale (BBS) in exercise and control groups.



Fig 2. Pre- and post-intervention distance of 6 min walking test in exercise and control groups.

POSTER ABSTRACTS

Treatments and clinical trials - Poster

P09-002

THE EFFECT OF GROUP EXERCISE INTERVENTION ON PHYSICAL FUNCTION IN ELDERS WITH MILD AND MODERATE DEMENTIA

Jung-Cheng Yang¹; Ms. Jui-Chi Hsu¹; Yu-Lin Lai¹; Ms. Yi-Chun Chein¹; Yi-Chen Tsai¹; Yi-Hui Lu¹; Hsiao-Ting Tsai¹; Hsiao-Yuan Lee¹; Yu-Ying Chu² and Ching-Fei Lo¹, (1)Phys Med & Rehabil, National Taiwan University Hospital Hsin-Chu Branch, Hsin-Chu, Taiwan, (2)Nursing Department, National Taiwan University Hospital Hsin-Chu Branch, Hsin-Chu, Taiwan

Abstract:

Background: In Taiwan, over 270 thousand people are diagnosed with dementia in 2017, with the prevalence rate around 8% in elders above 65. Group exercise intervention is a non-pharmacological treatment for dementia that can improve the physical fitness of elders and maintain their quality of life. By setting up dementia community care centers, burdens can be lightened for caregivers and for social economy.

Objective: This study was to investigate the effect of a 12 week group exercise intervention on physical function in elders with mild and moderate dementia in a community care center and it's continuity after another 12 weeks of cognitive training.

Method: Participants were elders diagnosed with mild and moderate dementia (CDR 1~2). Intervention included 12 weeks of exercise training followed by 12 weeks of cognitive training. Assessment was done before intervention, after exercise training, and again after cognitive training. Measurements included arm curl, chair stand scores for strength and muscular endurance; chair sit-&-reach (CSR), back scratch scores for flexibility; 8-Ft Up-&-Go for mobility; Functional Reach Test (FRT) for balance; the 6-min walk test for cardiopulmonary endurance. Group exercise included badminton, soccer, modified golf, racquetball, baseball, stair climbing, modified croquet, weightlifting with water bottles, theraband and towel exercises, and mat activities. Outdoor field trips were also arranged. Cognitive training focused on upper limb activities, cognition, and group discussions. The independent t test was used to compare the difference before intervention and after group exercise training, and before intervention and after cognitive training.

Result: 10 people participated, 3 males and 7 females, average age 84.3 years old. There were significant differences in all outcomes measurements between baseline and after exercise training scores, except the arm curl ($p=0.05$) (Table 1). As for baseline and after cognitive training, there were significant differences in the arm curl, chair stand, CSR, back scratch with left hand on top, and FRT ($p<0.05$); there weren't significant differences in back scratch with right hand on top, the 6-min walk test and the 8-Ft Up-&-Go scores (Table 1).

Discussion: Previous studies show that exercise is an effective way to delay the physical fitness decline or improve the fitness of elders with dementia, which is similar to our result. Exercise intensity was lower during cognitive training, causing a decrease in the effects gained after exercise training in mobility and balance. However, when elders came for group activity, their activity level increased, thus continuing the effect of exercise training on lower limb strength, flexibility and balance.

Conclusion: According to our results, elders with dementia can improve their physical fitness after receiving 12 weeks of group exercise in the community care center, and maintain a better physical condition if they continue to participate in community activities.

Table1. The outcome of all variables in the baseline(T0), after exercise intervention(T1) and after cognitive training(T2).

Variable	T0	T1: 12 weeks	P-value between T0 and T1	T2: 24weeks	P-value between T0 and T2
Arm curl	13.8 ± 4.8	16.4 ± 3.0	0.05	17.6 ± 2.7	0.004*
Chair stand	10.2 ± 2.0	13.1 ± 3.5	0.003*	15.0 ± 2.9	<0.001*
CSR(RT)	11.0 ± 11.7	-0.35 ± 12.6	<0.001*	2.6 ± 9.8	<0.001*
CSR(LT)	11.4 ± 12.5	0.3 ± 12.2	<0.001*	1.9 ± 11.2	<0.001*
Back scratch(RT)	11.0 ± 10.5	-6.6 ± 9.7	0.032*	-8.3 ± 10.8	0.213
Back scratch(LT)	18.9 ± 14.1	-13.0 ± 12.4	0.002*	-14.4 ± 11.5	0.012*
8-Ft Up&Go	9.8 ± 2.0	7.7 ± 2.3	<0.001*	10.2 ± 2.4	0.310
FRT	20.2 ± 4.3	27.8 ± 5.4	0.003*	25.9 ± 5.2	0.014*
6 min walk test	308.6 ± 102.8	356.1 ± 64.0	0.045*	325.4 ± 77.4	0.523

* $p<0.05$



P09-003

EFFECTS OF DEEP TOUCH PRESSURE ACTIVITIES WITHIN LIGHT-MODULATING ENVIRONMENT IN PERSONS WITH DEMENTIA

Ms. Huang-Ju Chi, Dementia Center, Taoyuan Chang Gung Memorial Hospital, Taoyuan, Taiwan; Dr. Wen-Chuin Hsu, Chang Gung Dementia Center, Taoyuan Chang Gung Memorial Hospital, Taoyuan City, Taiwan and Hsin-Yung Chen, Department of Occupational Therapy & Graduate Institute of Clinical Behavioral Sciences, College of Medicine, Chang Gung University, Taoyuan, Taiwan

Abstract:

Introduction:

Dementia leads to the progressive decline of cognitive functions such as attention, memory, reasoning, and executive function which are significantly affected to the performance of everyday activities. In addition, behavioral and psychological symptoms, including agitation, depression, apathy, anxiety, and sleep disturbance, often influence the quality of life for persons with dementia (PWD). Previous researches indicated that multi-sensory intervention has been inconclusive regarding the effectiveness of light therapy in improving night-time sleep, reducing agitation and improvement in purposeful performance for PWD. Furthermore, the deep touch pressure (DTP), carried by the dorsal column system, is believed to influence on autonomic activity and produce a calming effect through changes in physical arousal. It has been proposed that deep pressure touch influences both parasympathetic activity (though increased vagal tone, reflecting parasympathetic activity) and sympathetic activity (through reduces activation of the stress response, reflecting reduced sympathetic activity). Although both light therapy and DPT interventions provide similar effect on behavioral regulation, evidences is scarce to support the efficacy between the DTP as well as combined with light-modulating environment in PWD.

Objectives: To investigate the effect of the combination of DTP input activity training and light-modulating environment versus conventional purposeful activities for behavior performance on PWD.

Methods: A 2×2 mixed-model repeated-measures design was employed, deep touch pressure input activity training with light exposure group (light exposure group versus placebo exposure control group) serving as a non-repeated factor and time of testing (pre-evaluation period versus post-evaluation period) serving as a repeated-measures factor. Random assignment to groups was used to minimize potential confounding of PWD as well as light exposed to full spectrum light therapy 10000 lux or standard fluorescent tube light at 100 lux for two hours during 8 weeks purposeful activity training program between 10 am and 12 noon.

Results: The intervention of DTP activity within Light-modulating environment was associated with significant improvement in cognitive functions, and decreasing anxiety and agitation, while participants receiving placebo light displayed higher levels of anxiety and agitation or no significant change.

Conclusion: Findings support that DTP activity within light-modulating environment improve the performance of the purposeful activities and reduce anxiety and agitation of PWD.

Reference:

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POSTER ABSTRACTS

Treatments and clinical trials - Poster

P09-004

GLOBAL SYNCHRONIZATION INDEX AS A NEW INDICATOR FOR TRACKING COGNITIVE FUNCTION CHANGES BY TRANSCRANIAL DIRECT CURRENT STIMULATION IN TRAUMATIC BRAIN INJURED PATIENT: A CASE REPORT

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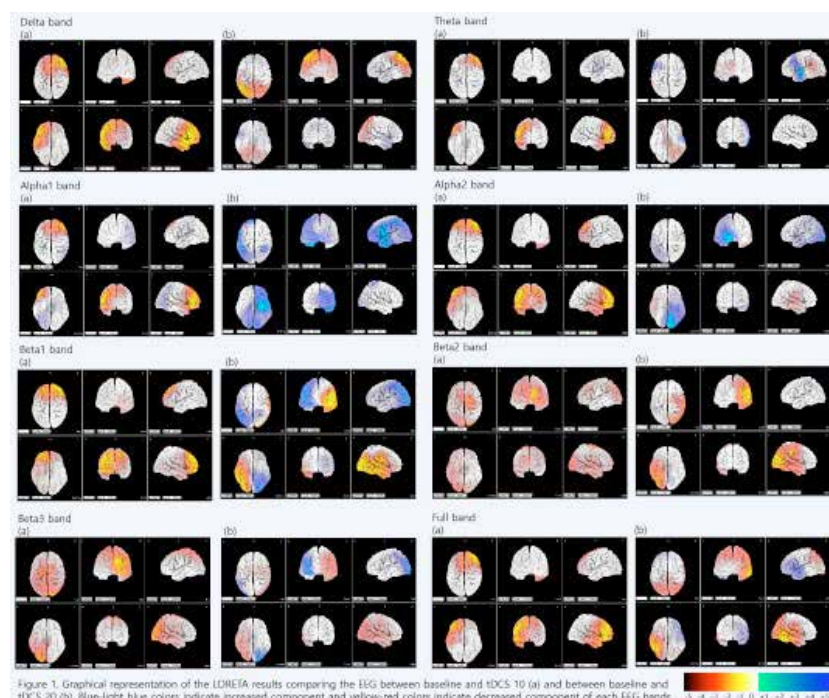
Abstract:

Objective: Traumatic brain injury (TBI) is a leading cause of long-term neurological disability such as cognitive impairments and executive dysfunction. Noninvasive transcranial direct current stimulation (tDCS), which can change brain excitability, was introduced and has been applied for therapeutic purposes regarding cognitive dysfunction after TBI. We investigated the effect of tDCS on the cognitive function and cortical power distribution by dual analysis of resting state Electroencephalography (EEG) with Global Synchronization Index (GSI) and Low-Resolution Brain Electromagnetic Tomography Analysis (LORETA) in a TBI patient.

Method: A 77-year-old male, who went through a traumatic brain injury showed severe impairment of cognitive function. We performed 20 sessions of 2mA tDCS over the left dorsolateral prefrontal cortex (DLPFC) and measured Korean version of the Mini-Mental Status Examination (K-MMSE) and Rancho Los Amigos (RLA) level at baseline, 10 days and 20 days each after tDCS. EEG was also performed on same days with K-MMSE and RLA tests.

Result: After tDCS, the cognitive function measured by K-MMSE and RLA level were improved. GSI showed decrease in the low frequency band (theta wave) and increase in high frequency bands (alpha and beta wave) (Table 1). LORETA analysis showed increased cortical activation components in high frequency bands at 20 days after tDCS (Figure 1).

Conclusion: We suggest that tDCS might be effective in TBI patients, and the alterations of cognitive networks could be effectively studied using GSI analysis together with LORETA.





POSTER ABSTRACTS

Table1. Cognitive function and GSI values

		Baseline	tDCS 10	tDCS 20
Cognitive				
Function	K-MMSE	3	4	10
	RLA level	5	5	6
GSI	Delta	0.3391	0.3314	0.4083
	Theta	0.3770	0.3730	0.3655
	Alpha	0.3101	0.3172	0.3529
	Low Beta	0.2830	0.2474	0.4289
	Beta	0.3083	0.2118	0.4289
	High Beta	0.4660	0.2986	0.5656
	Gamma	0.5805	0.4147	0.6262





POSTER ABSTRACTS

Treatments and clinical trials - Poster

P09-005

USE OF MEDICINES IN PEOPLE WITH DEMENTIA: PROBLEMS AND SOLUTIONS

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Abstract:

Objective: To provide a holistic view of quality use of medicines (QUM) in people with dementia and how to improve it

Method: Literature searches were conducted using MEDLINE, EMBASE and the Cochrane Library of Systematic Reviews databases from conception to August 2017 with limitation to English language. Key search terms included quality use of medicines, medication related problem, dementia and Alzheimer's disease

Result: Dementia is complex, involving deterioration of cognitive function, physical function and behavioural function. It is primarily a disease of old age and often coexists with other chronic diseases. As a consequence, people with dementia often take multiple medicines. This together with the progressive cognitive deterioration and age-related changes in pharmacokinetics and pharmacodynamics in older people with dementia increases the risk of medication related problems, treatment conflicts and poor treatment outcomes. Dementia clinical practice guidelines rarely address coexisting conditions. Evidence on which guidelines are based is mainly from clinical trials of small sample sizes and short-term follow-up that often exclude those with multiple chronic diseases and are not representative of the real-world population of people with dementia. While there has been no curative treatment, the existing evidence shows modest efficacy and significant adverse effects of pharmacotherapies for symptomatic treatments of dementia

Conclusion: Judicious selection of dementia management options, considering the place for non-pharmacological therapies, is critical. Also important is appropriate choice of medicines, where a medicine is considered necessary, and using them safely and effectively. These require the increasing involvement of pharmacists to provide a number of cognitive services including medication reconciliation, medication review, adherence services and proactive adverse reaction monitoring. A multidisciplinary, patient-centered, integrated and coordinated model of care is required to improve QUM and health outcomes for people with dementia



POSTER ABSTRACTS

Treatments and clinical trials - Poster

P09-006

PARTICIPANT EXPERIENCE OF ENGAGEMENT IN SIMULTANEOUSLY STIMULATING, COGNITIVELY, AND PHYSICALLY DEMANDING INTERVENTIONS: A QUALITATIVE STUDY EMBEDDED WITHIN A PILOT RANDOMISED CONTROLLED TRIAL

Kristina Alexandra Zawaly^{*1}; Stephen Buetow¹; Ngaire Kerse²; Lynette J Tippet³; Christina Ilse⁴ and Suzanne C Purdy³, (1)General Practice and Primary Healthcare, The University of Auckland, Auckland, New Zealand, (2) School of Population Health, The University of Auckland, Auckland, New Zealand, (3)Psychology, The University of Auckland, Auckland, New Zealand, (4)Anatomy and Medical Imaging, The University of Auckland, Auckland, New Zealand

Abstract:

Objective: The aim was to explore and understand participants' narratives with regard to their experience of taking part in a pilot study evaluating the feasibility and acceptability of conducting a randomised controlled trial (RCT). The RCT investigated the effects on cognitive and physical function of engaging in demanding interventions that are simultaneously stimulating, cognitively and physically.

Method: We undertook a qualitative study, embedded in a pilot RCT, in which 30 participants with mild cognitive impairment were equally randomised into the Ronnie Gardiner Method, free-movement dance, and seated music appreciation study arms. Three participants from the seated music appreciation group withdrew due to lack of interest and one participant from the Ronnie Gardiner Method was hospitalized preventing follow-up assessment. Twenty-one of the 26 participants who participated in follow-up data collection also provided narrative responses to four opened ended questions. We used Thematic Analysis to explore the transcribed data.

Result: Four themes emerged in relation to the participants' experience regarding components of the interventions that influenced their engagement. The themes comprise: (1) interpersonal dynamics, (2) scope of intervention, (3) expectations, and (4) received benefits. Most participants described a combination of the themes related to the nature of the interventions provided, as well as the themes related to perceived intervention effects.

Conclusion: The thematic analysis indicated that future intervention studies may benefit from: facilitators who can provide autonomy and support to participants, good group dynamics and social interaction, and applying the suggested alterations to the format and organization (e.g., timing) to improve experiences. These were among the themes that emerged that could contribute to better participant retention and provide breadth and depth regarding how the interventions could be improved. The participants' experiences contribute to our understanding of the acceptability for the planning and implementation of a definitive trial.





POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-001

THE EFFECT OF INTEGRATIVE COGNITIVE AND PHYSICAL TRAINING PROGRAM ON IMPROVING COGNITIVE FUNCTIONS AND ASPECTS OF FRAILITY OF OLDER ADULTS WITH MILD COGNITIVE IMPAIRMENT: A PILOT STUDY

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Abstract:

Objective: A report released by the World Health Organization in 2016 indicated that 7.7 million new cases of dementia were added each year; implying one patient was diagnosed with dementia every three seconds. The prevalence rate of dementia among Taiwan's elderly population over the age of 65 is 7.98%, and is estimated to reach 720,000 people by 2056. Dementia is a progressive deterioration of the cognitive function. In addition to the suffering of the patients themselves, similar physical, psychological, social and economic burden and stress also fall on the family and caregivers. Currently, several studies have demonstrated that cognitive and behavioral symptoms can be improved through cognitive training. Therefore, the objective of this study is to test the effect of integrative cognitive and physical training program on improving cognitive functions and aspects of frailty of older adults with mild cognitive impairment (MCI).

Method: The study used a pretest-posttest design. The research subjects were collected from 65 years old and above with mild cognitive impairment from Min Guang district in Taichung, Taiwan. The integrative cognitive and physical training program was 12 weeks long, and took place twice a week for two hours. Each session included 0.5 hours of physical exercise, 1 hour of cognitive training, and 0.5 hour social activity. Mini-Mental State Examination (MMSE), Activity of Daily Living (ADL) and Kihon Checklist were used to measure the effect of the intervention.

Result: A total of 23 older adults with MCI were studied. The average age of the study subjects were 81.22(±9.59) with 73.9% being female. Comparing the results before and after the intervention with the paired-t test showed that cognitive functions of the subjects improved after the training (Table 1). In addition, results of ADL and Kihon Checklist after the intervention have shown a positive progress (Table 2). In particular, the following aspects of frailty of the subjects substantially improved: ambulation, ability to go out by bus or train by one, ability to stand up from a chair without any aids, frequency of having a dry mouth, or experiencing helpless feelings in the last 2 weeks.

Table 1. Cognitive function before and after intervention (N=23)

item	Before		After		Paired-t test	
	mean	SD	mean	SD	t	p-value
MMSE	18.35	4.386	20.04	4.857	-5.456	<0.001

Note: $p < 0.01$



POSTER ABSTRACTS

Table 2. Aspects of frailty before and after intervention (N=23)

item	Before		After		paired-sample-T test	
	mean	SD	mean	SD	t	p-value
ADL total	1.65	1.90	1.17	1.83	2.71	.013*
Ambulation	.30	.51	.17	.39	3.10	.005*
Kihon Checklist	11.83	5.28	9.17	3.21	2.57	.017*
Do you go out by bus or train by yourself?	.74	.45	.43	.51	2.61	.016*
Do you normally stand up from a chair without any aids?	.52	.51	.26	.45	2.79	.011*
Do you often experience having a dry mouth?	.61	.50	.26	.50	2.34	.029*
In the last 2 weeks have you felt helpless?	.30	.47	.09	.29	2.47	.022*

Note: $p < 0.05$

Conclusion: According to the pilot study, the cognition and physical integrated training program significantly improves the cognitive function especially orientation ability and frailty aspects of mild cognitive impairment older adults. It is suggested that future study should enroll more study subjects to further test the effectiveness of the program.





POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-002

LIVED EXPERIENCES WITH MEDICINE FOR PERSONS WITH MILD COGNITIVE IMPAIRMENT IN TAIWAN: A PILOT STUDY

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Abstract:

Objective: Adults over the age of 60 years are at risk for developing symptoms of dementia, such as mild cognitive impairment (MCI). MCI often results in the need for assistance with management of medications. In Taiwan, family members are the primary care-givers for persons with MCI; these family care-givers (FCGs) are also responsible for helping with management of medications. The experiences of how persons with MCI and FCGs manage medications are limited. Therefore, the purpose of this pilot study was to understand the lived experiences with medicine for persons with MCI in northern Taiwan. The experience of care-giver medication administration hassles for FCGs were also explored.

Method: This was a multiple-case pilot study to recruit six pairs of persons with MCI and their FCGs with a purposively sampling method. This mixed-methods study developed interview guides for both the patient with MCI and the FCG to understand their medication use experiences. Patients were also evaluated with the Mini Mental State Examination (MMSE), Clock Drawing Test (CDT), Geriatric Depression Scale-short form (GDS-S), Medication Adherence Behavior Questionnaire (MABQ); FCGs were also evaluated with the Family Caregiver Medication Administration Hassles Scale (FCGMAHS). Approval was obtained from the Institutional Review Board of the study hospital (IRB # 101-0815B).

Result: Interview data showed persons with MCI reported medication-related burden as the primary factor influencing quality of life. Participants talked about at least one of the following five subthemes: (1) burden of medication routines, (2) burden of medication characteristics, (3) burden of medication-adverse events, (4) healthcare and associated medication burden and (5) medication-related social burden. FCGs reported that they themselves had multiple medications and various chronic diseases. When taking care of patients, they prioritized patients' needs and put aside their own needs. The responses to the patients' questionnaires reflected similar issues mentioned in the qualitative interviews, such as failure to maintain their medication routine. Findings from the FCGMAHS showed Scheduling Logistics were a hassle for FCGs: a mild hassle for 60%, and a moderate hassle for 50%. Safety issues for FCGs were considered a mild hassle for 30% and a moderate hassle for 30%. However, the top two hassles for our FCGs consisted of understanding the directions and information they were given, and knowing when to hold, increase, or decrease a dose, and when to discontinue medication. Therefore, obtaining and understanding information regarding medications and knowing how and when to administer medications were primary hassles for FCGs of persons with MCI.

Conclusion: Both persons with MCI and their FCGs faced certain patterns of difficulties in managing medications. Persons with MCI experienced medication-related burdens; FCGs experienced moderate hassles of medication management involving understanding directions and scheduling medications. Therefore, future research should focus on developing effective interventions involving multidisciplinary approaches to reduce the medication burden for persons with MCI and medication administration hassles for FCGs.



POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-003

CONDUCTING PSYCHOTHERAPY GROUPS WITH INDIVIDUALS WITH MILD COGNITIVE IMPAIRMENT (MCI)

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Abstract:

Conducting psychotherapy groups for older adults is both a rewarding and challenging opportunity. As we age, we experience different issues both emotionally and physically that can impact our mental health. We often explore life's meaning and purpose within our own perceptions as well as process through the psychosocial stages as described by Erik Erickson and other theorists. However, as someone starts to experience cognitive changes, this can impact their ability to participate, engage, and process within a group context. 3 years ago, as part of our Intensive Outpatient Program, we created a group specific to those who have mild cognitive impairment. We deemed it important to offer the opportunities of a mainstream psychotherapy group in a smaller group setting. This included occurring for a shorter period of time to best accommodate different needs. We identified both challenges and rewards of having this type of group. Overall, we found this addition to our practice to be extremely valuable for people identified as having Mild Cognitive Impairment. By being a part of this group, they are better able to navigate the emotions and struggles of this stage of life, including identification of life role transition, acceptance of physical and cognitive changes, and acknowledgement of self-worth and value.



POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-004

EFFECTS OF CREATIVE EXPRESSION THERAPY FOR OLDER ADULTS WITH MILD COGNITIVE IMPAIRMENT AT RISK OF ALZHEIMER'S DISEASE: A RANDOMIZED CONTROLLED CLINICAL TRIAL

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Abstract:

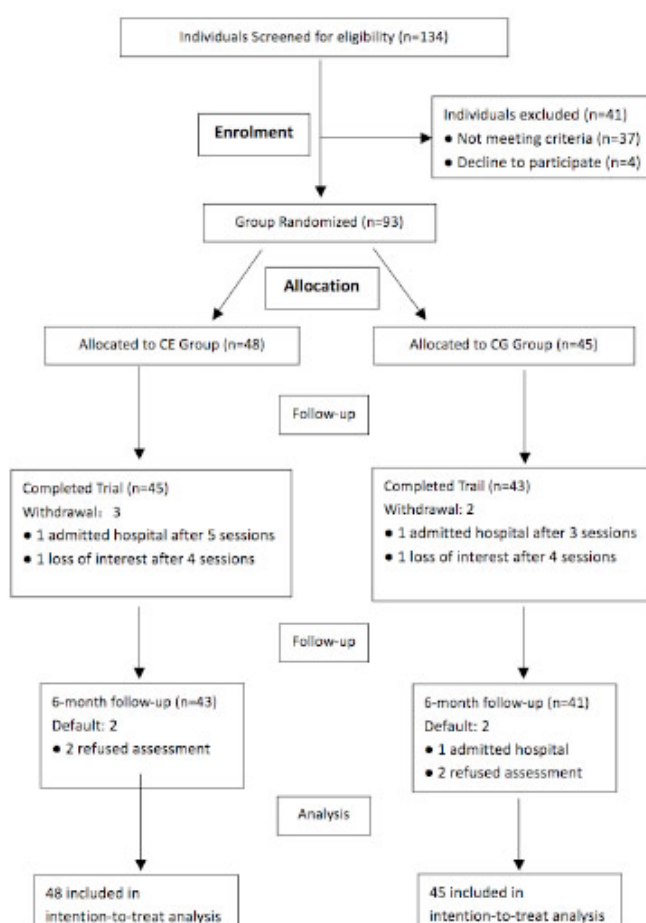
Objective: Elderly people with mild cognitive impairment (MCI) are at a high risk for dementia. The current study compared the effects of standard cognitive training to a creative expression program.

Method: Adult patients aged 60 years and over with MCI (N = 93) were randomly assigned to either creative expression therapy (CrExp) (n = 48) or a control group (CG) that received standard cognitive training (n = 45) for 16 weeks. The Montreal Cognitive Assessment, Chinese-version Auditory Verbal Learning Test, Chinese-version Verbal Fluency Test, Digit Span Test, Trail Making Test, Chinese-version Activities of Daily Living Scale and Memory Satisfaction Questionnaire were used to measure cognitive functioning and daily living abilities. Assessments were administered at baseline, post-intervention and at a 6-month follow-up.

Result: Post-intervention, patients receiving CrExp therapy scored significantly higher than patients receiving standard cognitive training in general cognitive functioning, memory, executive function, functional status and everyday living ability. The improvements in cognitive functioning were maintained at the 6-month follow-up.

Conclusion: CrExp therapy has greater positive effects on cognitive functions and daily living ability than standard cognitive training. This unique therapy may serve as a cost-effective adjunct to standard interventions for older adults with mild cognitive impairment.

Figure 1. Study flow chat





POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-005

A COMPARATIVE SINGLE-BLIND RANDOMIZED CONTROLLED TRIAL WITH LANGUAGE TRAINING IN PEOPLE WITH MILD COGNITIVE IMPAIRMENT

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Abstract:

Objective: Cognitive training is effective for people with Mild Cognitive Impairment (MCI). However, it is not clear which format of cognitive training is more effective. The aim of this study was to compare the effectiveness of the same language training program when it is carried out via computer, paper and pencil or orally, in comparison to two different control groups, an active (AC/G) and a passive one (C/G).

Method: The cognitive training in this study aimed primarily to the enhancement of specific language skills via paper and pencil (PP/G), oral (OR/G) and computer-based (PC/G) tasks. Seventy one participants (N=71) with MCI, were classified randomly in three experimental and two control groups, matched in age, gender, and education. The experimental groups attended 48 sessions of language training twice a week for six months. At the same time, an AC/G attended 48 unstructured sessions with discussion of current events. The second C/G followed the regular activities of daily life without any kind of intervention (waiting list). Neuropsychological assessment was performed at baseline and six months later, at the end of the study.

Result: At the follow up, there was a significant difference among the 5 groups in verbal fluency ($p \leq 0.007$), in repetition ($p = 0.009$) and in phonemic correlation ($p = 0.009$). Specifically, PC/G had better performance than AC/G and C/G in verbal fluency ($p \leq 0.042$). PP/G had better performance than PC/G in repetition ($p = 0.011$) and in phonemic correlation ($p = 0.017$). The OR/G had better performance than AC/G and C/G in verbal fluency ($p \leq 0.046$) and outperformed the PC/G group in repetition ($p = 0.047$). The AC/G had better performance than PC/G in phonemic correlation ($p = 0.023$). At the end of the language training PC/G group showed improvement in verbal fluency ($p = 0.019$) and in verbal memory ($p = 0.036$), while deterioration was noticed in phonemic correlation ($p = 0.013$). The PP/G showed improvement in verbal fluency ($p = 0.000$), in phonemic correlation ($p = 0.035$), in reading comprehension of sentences ($p = 0.003$), in repetition ($p = 0.037$), in semantic memory ($p = 0.010$), and in activities of daily living (ADL) ($p = 0.012$). The OR/G improved in verbal fluency ($p = 0.000$), in semantic memory ($p = 0.012$), in digit span ($p = 0.025$), and in learning ability ($p = 0.011$). The AC/G and the C/G stabilized their performances.

Conclusion: There is no evidence of which format of language training is the most effective since all the experimental groups improved their cognitive abilities. However, the paper and pencil version seems to be more effective regarding to the transfer of the cognitive benefit to ADL.



POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-006

WHY CAN I HEAR BUT NOT UNDERSTAND?

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Abstract:

Objective: “As life expectancy continues to increase around the world, the need for new ideas on how to create an environment that is stimulating for all the senses is becoming more and more urgent. It is our senses that deliver information on the current state of our environment and our body's position in relation to it. Every part of the body is involved in this process, but as we age, our senses may become impaired, reducing our ability to process sensory information. Architectural design appropriate both for the elderly and for people suffering from dementia can facilitate this processing of sensory impressions, minimizing any potential misinterpretations and helping to preserve the competencies of this group of the population as long as possible.

Impairment of central auditory processing is a well-known symptom of neurodegenerative dementia. However, whilst numerous studies have examined verbal processing impairment, to date few have attempted to describe impairments of non-verbal, environmental sound recognition in patients with dementia. As these impairments may have direct implications on patient support and care, such studies are urgently necessary.

The aim of the study was to determine whether the recognition of meaningful environmental sounds is impaired in patients with mild or early stage neurodegenerative dementia.”

Method: “We developed a test of non-verbal sound recognition consisting of 16 sound sequences from the living and non-living environment. We included 18 patients with mild cognitive impairment and mild dementia owing to Alzheimer's disease and frontotemporal dementia, as well as 20 cognitively healthy controls.”

Result: “Patients and controls were given the test of recognition of 16 meaningful sounds from the living and non-living environment. Patients with dementia performed significantly worse in comparison to cognitively healthy controls. Whilst healthy controls correctly recognized $12,1 \pm 2,2$ out of 16 sounds, cognitively impaired patients recognized $9,2 \pm 2,5$. Correlation analysis showed that the Mini-Mental-State-Examination (MMST) scores were positively correlated with the number of correctly recognized sounds (MMST: $r = 0,556$; $p = 0,017$).”

Conclusion: The fact that patients even in mild stages of Alzheimer's disease or frontotemporal dementia either do not recognize or misinterpret environmental sounds must be taken into consideration, not only in everyday life, but in particular when patients need to leave their familiar living environment, whether temporarily (e.g. hospitalization) or permanently (e.g. nursing home admission). We are thinking about developing a test for cognitive impairment that focuses on auditory rather than visual information for people with a visual impairment, as the recognition of meaningful environmental sounds is impaired in patients with mild or early stage of dementia.



POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-007

EFFICACY OF GAMIFICATION OF COGNITIVE TRAINING FOR OLDER ADULTS WITH MILD COGNITIVE IMPAIRMENT

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Abstract:

Objective: Persons with mild cognitive impairment (MCI) are at high risk for dementia. Cognitive-based intervention, such as game-based cognitive training for persons with MCI to prevent their further deterioration, is crucial in clinical practice. However, there was no sufficient evidence to support the efficacy of game-based cognitive training for persons with MCI. There was also no study to compare the effects of cognitive training between different formats of the intervention, individual and group.

The purpose of this study was to investigate the efficacy of a board game based cognitive training program on the enhancement of cognitive functions, namely attention, memory and executive function. We also compared the efficacy between group versus individual format.

Method: This was a single-blind, quasi-experimental study. The subjects included 18 older adults with a confirmed MCI from a neurologist. The participants were assigned either a group- or individual-based intervention. Both groups received a 12 session cognitive training program (1.5 hours for each session, twice a week). The primary outcomes included the general cognitive function (Montreal Cognitive Assessment-Taiwan Version), selective/divided attention (Test of Everyday Attention), immediate/delayed visual memory (Contextual Memory Test), immediate/delayed verbal memory (The Rivermead Behavior Memory Test-Third Edition), processing speed (Symbol Digit Modalities Test), inhibition (Stroop Color and Word Test), visual spatial working memory (Cambridge Neuropsychological Test Automated Battery Spatial working memory), and emotional state (Geriatric Depression Scale). Outcomes were assessed pre- and post-test. The nonparametric statistics were used by Wilcoxon Signed Ranked Test (within group analysis) and Mann-Whitney U Test or Chi-Squared (between group analysis).

Result: The results showed significant improvement for all subjects in overall cognitive function, selective attention, delayed visual memory and immediate/delayed verbal memory after the intervention. Subjects in individual format showed significant within-group improvement in overall cognitive function, delayed verbal memory, inhibition, and visual space working memory. While subjects in group format improved significantly only in visual spatial working memory. However, there was no significant between-group difference of the changes on all outcome measures. Furthermore, subjects with low cognitive function (Clinical Dementia Rating – Sum of Boxes (3) had significantly improved visual space working memory after training in individual training format, whereas subjects with high cognitive function has only significant improvement in the emotional state after the group training.

Conclusion: The present study showed that applying a 12-session board-game cognitive training for older adults with MCI had positive effects on cognitive function enhancement, especially in general cognition and memory. With equal time of intervention, compared with group format, the individual format provide more opportunities for practices, can be more tailored to individuals' needs, and might result in better outcomes. Future studies need larger samples to validate this.





POSTER ABSTRACTS

Mild cognitive impairment (MCI) - Poster

P10-008

SUBJECTIVE COGNITIVE DECLINE (SCD) IN SWEDISH SHELTERED HOUSING

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Abstract:

Objective: A new form of housing for elderly people in Sweden, sheltered housing, that provides accessible apartments and social possibilities for older people who feel anxious, unsafe or lonely but are otherwise capable of independent living. It is expected that living in sheltered housing will increase the wellbeing of residents by enhancing social interaction and thus reducing anxiety. Currently, there are no studies of sheltered housing in Sweden and the frequency of subjective cognitive decline in this new form of housing.

Aim To examine prevalence of subjective cognitive decline and if it is a strong predictor of moving to sheltered housing in Sweden.

Method: A cross sectional survey study with controls (n=3805) matched on age, gender and municipality. Descriptive statistics, frequencies, t-tests, and logistic regression were used to examine reasons of moving.

Results: SCD Initial analyses show lower self-rated health, lower functional status, those living in sheltered housing compared to aging in place. Further, a higher proportion of people in sheltered housing state that they experience subjective cognitive decline. Although this, higher proportion of subjective cognitive decline, it is not as strong predictor of moving to sheltered housing.

Conclusion: SCD is more prevalent in sheltered housing and this needs longitudinal follow up in order to be able to explore trajectories of cognitive decline, resource use and functional capacity of people living in sheltered housing.





POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-001

COMMUNICATION DIFFICULTIES: A SYNTHESIS OF EVIDENCE OF CURRENTLY AVAILABLE TOOLS USED TO ASSESS LANGUAGE AND COMMUNICATION IN DEMENTIA

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Abstract:

Objective: Language and communication abilities are affected early in the four most prevalent types of dementia. Accurate and timely assessment of language and communication impairment (LCI) is vital. The objective of this review is to provide a critical appraisal and synthesis of evidence concerning the best, psychometrically valid tools for the assessment of LCI in dementia.

Method: A broad scoping review of the literature was conducted to identify tools in English used for the assessment of LCI in dementia published between 1970-2017. Using a set of eligibility criteria, 18 tools were found most appropriate for dementia populations. The 18 tools were further examined for their psychometric properties and evidence for use in research and practice, using a systematic search of evidence (four major health databases, a google and google scholar web search, and snowballing) and a ten-point scoring system.

Result: Three tools received an objective score of ten points (highest). The *Arizona Battery of Communication Disorders of Dementia*¹ may be best used for the comprehensive assessment of clinical language and functional communication-related (dis)abilities in mild to moderate Alzheimer's disease. The *Sydney Language Battery*² demonstrated its superior capacity to screen language in Primary Progressive Aphasia (PPA) populations and help determine the PPA variant. The *Addenbrooke's Cognitive Examination III*³ was found to be best in gaining a broad understanding of language impairment as part of the neuropsychological cognitive function testing. Additional tools with a score of 9 points were also identified. A limitation of the top tools concerned limited standardisation for dementia types other than Alzheimer's disease.

Conclusion: This review provides recommended tools for the assessment of LCI in dementia, highlighting the best combination of evidence regarding psychometric properties and demonstrated utility in various clinical and research contexts. The findings can be useful for clinicians when choosing the most appropriate tool for their assessment, and in guiding their decision-making for the adequate management of communication difficulties among people living with dementia.

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POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-002

PERSON CENTERED AND COMMUNITY BASED TIMELY DIAGNOSTIC STRATEGIES OF DEMENTIA

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Abstract:

Objectives: Timely diagnosis of dementia refers to a diagnosis as early as first attention by someone, such as clinicians, family or friends because of concerns about changes in cognitive, behavior, or functioning. There are many barriers in providing timely diagnosis in practice. Patient or caregiver's willing, physical decline and knowledge gap are the usual causes of delay diagnosis. Providing person centered and community based strategies for timely diagnosis of dementia are essential.

How to do? We developed 3 levels of strategies for timely diagnosis of dementia. The potential people with cognitive decline had been referred from community. Firstly, we referred the people to hospital based memory clinics for comprehensive assessment and testing. Secondly, for the people who is not capable of or unwilling to hospital based memory clinics, we referred this patient to nearby community clinics. Thirdly, the people with cognitive decline who had difficult in mobility or unwilling to receive medical services had been referred to home care services. We did home visit by the group of neurologist, psychologist and case manager and provided history taking, physical examination and essential cognitive testing. The residual testing had been done in hospital with organized and smooth "green pathway" in one day.

Conclusion We provided person centered and community based regarding above 3 levels of diagnostic strategies to achieve the goal of timely diagnosis. This new strategies can solve most barriers of physical disability and accessibility of medical services. Early diagnosis potentially offers the opportunities of early intervention, implementation of coordinated care plans, and better management of symptoms and possible slow disease progression which are useful to people with dementia.





POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-003

WHAT ARE THE MOST IMPORTANT SUPPORT ACTIVITIES FOR PEOPLE AFTER A DIAGNOSIS OF DEMENTIA? LEARNING FROM THE EXPERIENCES OF PEOPLE WITH DEMENTIA. ---- CO-PRODUCTIVE RESEARCH BETWEEN PEOPLE WITH DEMENTIA AND RESEARCHERS

Tetsuro Ishihara^{*}, Miharunomori Clinic Japan; ECRED, Sendai, Miyagi, Japan; Mr. Tomofumi Tanno, Orange Door; Working Group Miyagi, Sendai, Miyagi, Japan; James McKillop, Dementia Activist, Glasgow, Scotland, United Kingdom; Akiko Ishihara, Graduate Program on Negotiation, Conflict Resolution, and Organizational Management, Kumamoto University, Kumamoto, Japan and Hideki Yamazaki, Izuminomori Clinic, Sendai, Miyagi, Japan

Abstract:

Background:

People with dementia have a right to get support for living with the disease. Moreover, it is also guaranteed by the Convention on the Rights of Persons with Disabilities. Each country, including Japan, has a post-diagnostic support system. However, there are dozens of cases where people couldn't get USEFUL support just after diagnosis which resulted in a difficult time for them. In Japan, several people with dementia, the "Dementia Activists", have talked about their after-diagnosis experiences in front of a large audience, and have given suggestions for proper post-diagnostic support.

Objectives:

- 1) To determine proper post-diagnostic support for people with dementia so that they may live effectively with the disease by analyzing their revitalization process after diagnosis.
- 2) To find methods of motivating people with dementia to talk about their experience in public.

Methods: We performed a content analysis on public discussions in which people with dementia talked about their experiences after diagnosis and suggested proper diagnostic support. The public discussions were held twice in January of 2018. The participants of the first public discussion were people with young onset dementia (n=4), and the participants of the second discussion were not limited by age (n=4). They had been diagnosed by one or more dementia specialists. They talked about their experience of how the diagnosis impacted on their lives and how they recovered from it. Their conversation was recorded on video, and dementia activists and researchers analyzed it collaboratively.

This investigation was approved by the ethics committee at the author's organization, and all participants consented to the investigation.

Results: Several important factors were found in the processes that people with dementia used to rebuild and revitalize their meaning of life after diagnosis.

1. Finding a specialist (including medical doctors, nurses, and care specialists) who supported them psychosocially and who recommended them to meet other people with dementia for peer support
2. Talking with friends about the symptoms of dementia
3. Get person-centered support from their family.



POSTER ABSTRACTS

Proper post-diagnostic support should include,

1. Support by dementia specialists to connect post diagnostic people to peer support groups
2. Good peer support communities of people with dementia
3. Raised awareness about post diagnostic support of dementia among friends and family members.

The reasons for motivating people with dementia to start talking about their experiences in public were

1. the desire for citizens to understand the struggle of those with dementia
2. to support other people with dementia
3. because one Dementia Activist had been an expert of another disease before being diagnosed.

Conclusion: Many people with dementia said it was important to meet other people living successfully with the disease. The preliminary results of the investigation in Japan went to support the Dementia without Walls programme (<http://dementiawithoutwalls.org.uk/>), the Dementia Alliance International (<https://www.dementiaallianceinternational.org/>), DEEP network (<http://dementiavoices.org.uk>) and many other programs. We included medical professionals who need knowledge of this resource for peer support and provided them with information for social prescribing or post-diagnostic support.

Further systematic investigations are needed to strengthen this research.





POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-004

CHANGES IN THE HIPPOCAMPAL VOLUME AND SHAPE IN EARLY-ONSET MILD COGNITIVE IMPAIRMENT

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Abstract:

Objective: The aim of this study was to examine the change in the hippocampal volume and shape in early-onset mild cognitive impairment (EO-MCI) associated with the APOE ϵ 4 carrier state.

Method: This study had 50 subjects aged 55-63 years, all of whom were diagnosed with MCI at baseline via the Korean version of the Consortium to Establish a Registry for Alzheimer's Disease Assessment Packet. The EO-MCI patients were divided into the MCI continued (MCIcont) and Alzheimer's disease (AD) converted (ADconv) groups 2 years later. The hippocampal volume and shape were measured for all the subjects. The local shape analysis (LSA) was used to conduct based on the 2-year-interval magnetic resonance imaging scans.

Result: There was a significant correlation between APOE ϵ 4 allele and hippocampal volume atrophy. Over two years, The volume reduction in the left hippocampus was found to be faster than that in the right hippocampus, especially in the APOE ϵ 4 carriers. LSA showed that the 2 subfields were significantly affected in the left hippocampus.

Conclusion: These results suggest that the possession of APOE ϵ 4 allele may lead to greater predilection for left hippocampal atrophy in EO-MCI, and some specific subfields of the hippocampus may be more prominently involved.





POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-005

MAPPING THE FRONTAL ASSESSMENT BATTERY USING EVENT RELATED POTENTIALS

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Abstract:

Objective: a test such as the Mini Mental State Examination (MMSE) is effective only when there is mild cognitive impairment. However the Frontal Assessment Battery (FAB) is a test that evaluates frontal lobe functions/executive functions that can be used as an early indicator of dementia due to AD. The aim of the present study was to (a) automate the administration of the FAB, (b) verify if the subtests in the FAB result in distinctive frontal lobe event related potentials, and (c) interpret the contributions of different frequencies (delta, theta, alpha and beta).

Method: The software PsychoPy was used to conduct the FAB by building a flow, which contains the six questions in a particular order, using fixation segments, instructions, and trials. The FAB comprises six subtests, which assess the following; conceptual ability, mental flexibility, motor skills, sensitivity to interference, inhibitory control, and environmental autonomy of a subject. The questions and the order of sub trials were randomized. PsychoPy eliminates the need for manual intervention or monitoring, which additionally stores the response and response time for each question. Time-locked Electroencephalographic (EEG) activities, i.e., event-related potential (ERP) were obtained from 10 subjects continuously using a 32-channel geodesics EGI system with sponge based geodesic sensor net. The collected data was processed using the EEGLAB plugin in MATLAB to determine regions of maximum activity during different times of the experiment also a graph theoretic model was constructed using the EEG data.

Result: The spectral entropies were calculated, along with the Pearson correlation coefficient to understand the synchronization with respect to the electroencephalographic signals that takes place during the assessment; the delta waves were inversely correlated as compared to the theta, alpha and beta, which were positively correlated. A 32 node network was constructed for various band frequencies to determine the strength of connections between the anatomical regions and within the frontal lobe

Conclusion: 80% of the FAB was automated on the online platform and we were able to correlate the event and neuroelectrophysiological signals. The simple graph theoretic analysis helps in identifying key node that are vital in terms of FAB. The EEG analysis helps in correlating the respective frequencies and the corresponding questions from the FAB. Overall a general map of the FAB can be carried out using EEG as an ERP experiment.



POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-006

DISINTEGRATION ALGORITHMS OF MENTAL FUNCTION IN DEMENTIAS IN LATE AGE**Dr. Liubov Pishchikova**, Gerontological Protection, Moscow, Russian Federation**Abstract:**

Objective: International studies of aging processes are recognized by the UN and the WHO as global agenda issues, which is caused by the increasing number of late age person with dementia in the world. Incorrect diagnosis causes the phenomenon of ageism, treating "age" as synonym for "dementia", which can lead to a violation of rights of older people. Understanding the general patterns of loss of hinger mental functions, disintegration algorithms, is relevant for correct diagnosis and definition of the clinical form and stage of dementia, has anti-discriminational significance for patients of late age in psychiatry.

Method: Clinical and expert analysis of 235 late age patients (>60 years) who underwent forensic psychiatric examination in Serbsky Federal Research Center for Psychiatry and Narcology in criminal and civic cases, revealed: "non-dement" mental disorders - 45.5%, psychosis - 7.7%, dementia - 46.8% (dementia in Alzheimer's disease with early and late onset (F00) - 16.5%; mixed dementia (F00.2) - 39.4%; vascular dementia (F01) - 42.2%; amnesic syndrome (F04) - 1.8% (ICD-10).

Result: We have identified the following algorithms for the disintegration of hinger mental functions:

from the hinger to the lower (evolutionary earlier); from previously learned information and behaviors - to later ones; from emotionally neutral information - to emotionally more significant;

- from dysmnestic disorders (violation of reproduction, fixation) - to fixative amnesia - to progressive amnesia - to sensory aphasia - to agnosia - to motor aphasia - to apraxia;
- sequence of the stages of memory decline: from the later acquired information to the earlier one; from fixative amnesia - to progressive amnesia (retrograde) - to affective memory; from less hardened skills to more fixed ones;
- sequence of loss of orientation: disorientation in space (temporary, then constant) - in time - in place - in one's own personality.

Conclusion: Despite the existence of general disintegration algorithms of hinger mental functions, different types of dementia are characterized by a recognizable specific clinical picture and dynamics (syndromokinesis, progredness, cognitive deficiency structure).





POSTER ABSTRACTS

Diagnosis and imaging - Poster

P11-007

PLASMA TAU AND NEUROFILAMENT LIGHT CHAIN AS A PROGNOSTIC BIOMARKER OF DISEASE PROGRESSION IN EARLY ALZHEIMER'S DISEASE

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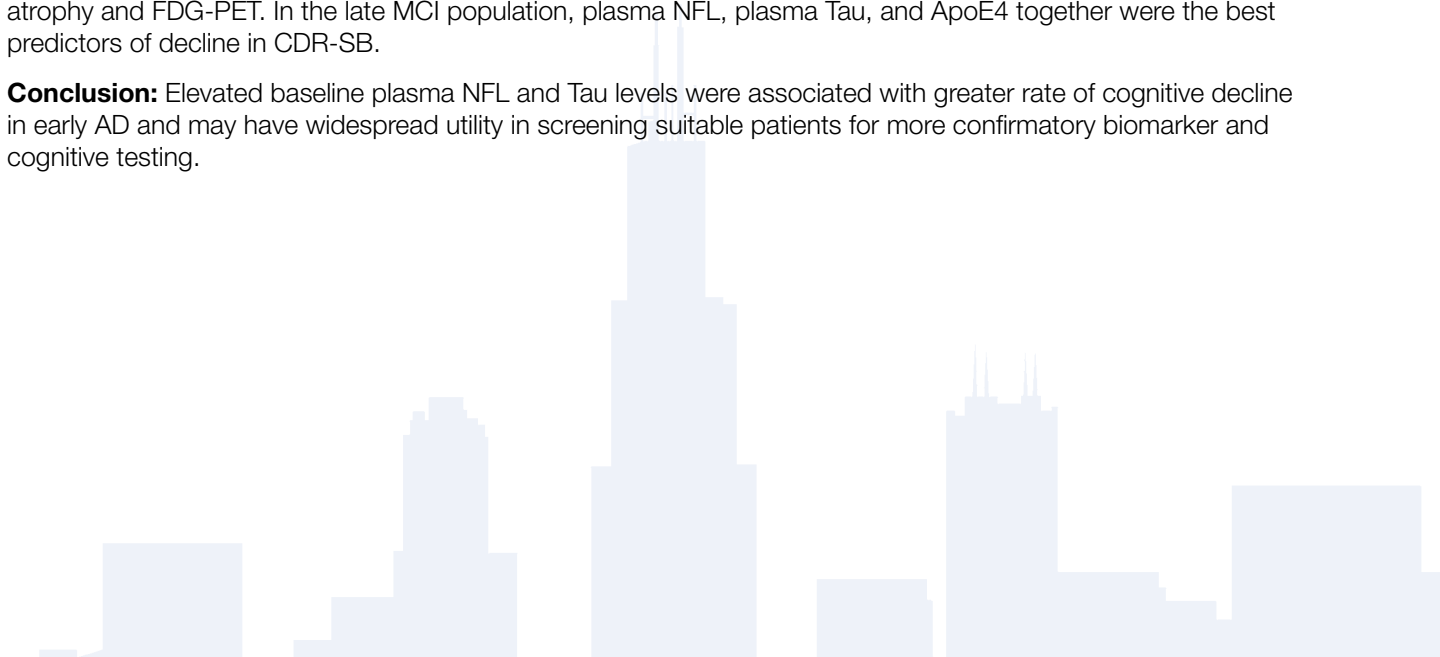
Abstract:

Objective: Clinical assessments alone do not accurately identify early Alzheimer's disease (AD) patients with relevant underlying molecular pathology and with greater risk of disease progression. Amyloid PET and cerebrospinal (CSF) A β /Tau biomarkers, in combination with measures of cognitive dysfunction, are critical tools to select patients eligible for early Alzheimer's disease clinical trials. Although imaging and CSF tools are powerful enrollment biomarkers, they can be costly and invasive in the context of high screen failure rates. Recent studies suggest that blood biomarkers such as A β , Tau, and neurofilament light (NFL) chain may differentiate AD from normal healthy controls, but the ability to predict underlying pathology and progression in early AD is limited when used individually. An analysis was conducted in a small cohort of AD, MCI, and controls and in publicly available Alzheimer's Disease Neuroimaging Initiative data to determine whether a combination of blood biomarkers predicts cognitive decline or is associated with amyloid positivity.

Method: Plasma samples were analyzed for Tau and NFL; data assessed as predictors of cognitive decline and relationship to MRI and PET imaging endpoints. For single biomarker analyses, both general and generalized linear models were used. Predictive power was estimated by the receiver operating characteristic curves approach. Predictions of progression utilized a multivariate analysis with a backward model selection procedure for decline at either two or three years' follow-up.

Result: Age was a critical co-variate in all models tested. Plasma NFL levels were elevated in late MCI and AD compared to controls, with only small elevations noted in plasma Tau. Elevated plasma NFL showed strong association with hippocampal atrophy and was predictive of decline in Clinical Dementia Rating-Sum of Boxes (CDR-SB). Performance of plasma NFL was similar to other predictors including amyloid PET, hippocampal atrophy and FDG-PET. In the late MCI population, plasma NFL, plasma Tau, and ApoE4 together were the best predictors of decline in CDR-SB.

Conclusion: Elevated baseline plasma NFL and Tau levels were associated with greater rate of cognitive decline in early AD and may have widespread utility in screening suitable patients for more confirmatory biomarker and cognitive testing.





Dementia friendly communities - Poster

P12-001

OPTIMIZING RESIDENT CARE AND QUALITY OF LIFE IN LONG-TERM CARE WITH ENVIRONMENTAL ENHANCEMENTS

Mr. Steven J. Crawford*, McCormick Care Group, London, ON, Canada; Iris Gutmanis, Department of Epidemiology and Biostatistics, Western University, London, ON, Canada and Catherine M. Blake, McCormick Dementia Research, McCormick Care Group, London, ON, Canada

Abstract:

Background/Objectives: Approximately 62% of Ontario's long-term care home (LTCH) residents have dementia¹ and 78% of those with dementia experience behavioural and psychological symptoms². In November 2014, all LTCHs in the South West LHIN (n=78) were invited to apply for \$5,000 in one-time funding for evidence-based environmental enhancements to help prevent or decrease resident responsive behaviours. Following a peer-review process, the 74 successful applicants were notified in January 2015. Projects were completed by March 31, 2015.

The majority of homes chose one of four approaches to reduce the frequency of responsive behaviours:

- more than half (56.8%) used the funding for multi-sensory equipment, such as Snoezelen™;
- 21.6% purchased expressive therapy equipment, such as iPods™ and iPads™;
- 21.6% created more home-like settings by purchasing new carpeting, tables, and chairs; and
- 17.6% camouflaged doors and other exit points in an effort to reduce elopement attempts.

Methods: In August 2015, five months after the enhancements had been put in place, the 74 participating LTCHs homes were surveyed and asked to:

- describe lessons learned;
- share any feedback from residents and family members;
- indicate if they would recommend this project to other homes, and
- describe what factors would be likely ensure success elsewhere.

Results: Fifty-two homes responded to the survey (70.3% response rate). All homes thought that the projects were valuable and had a positive impact on both residents and staff. The enhancements resulted in: decreased responsive behaviours; increased staff and resident engagement and quality of life; reduced depression; and enhanced communication among residents, their family members and staff. A number of homes reported that communication with residents, their family members, and staff about why projects were chosen and their expected impacts was key to success. Respondents also noted that making changes in a short time period can be challenging, but provided some advice on how to make such projects easier in the future, recommending that homes look at factors such as vendor support, policy development, and existing protocols.

Conclusion: This project shows that even with a relatively small amount of money, LTCHs can successfully implement evidence-informed environmental changes that decrease responsive behaviours and improve both resident and staff quality of life. Although staff members were aware of what needed to be changed, they lacked the funds to do so. This one-time funding allowed homes to implement changes that positively affected residents and staff alike, within a short period of time.

References:

1: Ontario Long-Term Care Home Association. (2015). This is Long-Term Care 2015. Retrieved from <http://bluetoad.com/publication/?i=281415>

2: Seitz, D., Purandare, N., & Conn, D. (2010). Prevalence of psychiatric disorders among older adults in long-term care homes: A systematic review. *International Psychogeriatrics*, 22(7), 1025-1039. DOI: <http://dx.doi.org/10.1017/S1041610210000608>.



POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-002

THE EFFECTIVENESS EVALUATION OF THE CARE PROGRAM PROMOTION TO DELAY DEMENTIA IN THE COMMUNITIES IN TAIWAN

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Abstract:

Objective: According to the demographics of National Development Council (2014-2016), the population aged over 65 will account for up to 14.6% in 2018, making our country an aged society. In 2025, it will be over 20%, making our country a super-aged society. There will be only seven years for the aged society to become a super-aged society. The aging speed is higher than other advanced countries.

The Taiwanese government proposed "White Paper on Aging Society" in 2015, which focuses on the principle of caring for all the elderly and at the same time shows concern for the need and service of the healthy, sub-healthy, and disabled elderly people. With the core spirit of "enhancing health," the policy aims to "increase the years of staying healthy, reduce the number of disabled elderly people" and responds to the impact of population aging in coordination with the long-term care system.

In 2017, the government established the community prevention care network targeting mainly at the frail elderly and those with the light or medium disability (dementia) to build up the "community-based" service system to prevent and delay disabilities.

Through the promotion of the community activities, this study aims to achieve the goal of disability prevention, dementia delay, and successful aging.

Method: The course was design for mild dementia, each elderly will participated in 2 hours a week for 12 consecutive weeks with the axis of "blocks, exercise, and communication" to provide the elderly with the chances to be involved in learning. In the beginning of each session contain 20 minutes of aerobic exercise to improve brain activity, follow by the cognition activity, such as communication with life story, group exercise and blocks. The life story will let the elderly to discover the happiness memories throughout their life by painting and writing. Manipulate blocks emphasizes hand-operated skill and cognitive association. The leader will encourage participants to create their own artwork.

The purpose of the exercise course is to have sufficient exercise intensity and duration integrate with cognitive games. Exercise content from functional activities of daily living such as dressing, sit to stand that will improve the balance control and muscle strength.

Result: After the course the elderly with mild dementia increase their intention to participate in the activities and be more willing to tell the stories about themselves. Through the design of the exercise game, they have improved their activity obviously, such as sit to stand ability, one leg standing ability and fitness. The blocks will increases their creativity and fine motor operation ability. Their social interaction of elderly was significant improve; all of them would like to participate the course long-term.

Conclusion: The course design based on the aerobic exercise combine cognitive activity with the axis of "blocks, exercise, and communication" is effect for the elderly with mild dementia to share life stories. The fitness and functional activity improvement will reduce the falling risk; the blocks improve fine motor skill and the concept of structured space.



POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-003

DEMENTIA FRIENDLY COMMUNITIES: DEMENTIA COUNSELLING CENTRES WITHIN MUNICIPALITIES IN GREECE

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Abstract:

There are 200,000 people living with dementia in Greece and 400,000 family carers looking after them. Although there is a National Action Plan for dementia and Alzheimer's disease in place and there are Memory Clinics and Day Care Centers for people with dementia in the large cities of Greece, compared to existing needs, services are woefully inadequate. Large areas of the country are not covered by any specialised facilities. Athens Alzheimer Association (AAA) in collaboration with the Greek *National Network of Healthy Municipalities* has developed a project for providing care to people with dementia and education and support to their carers in the local communities.

The project will be implemented in two phases.

1. *Currently 103 health and social care professionals from the 43 municipalities from all over Greece are participating in online synchronous and asynchronous training via virtual specially developed training platform. In total the training consists of 10 2-hour classes, followed by practical on the job training at the Day Care Centers of Alzheimer Associations in Athens and Thessaloniki.*
2. *As of April 2018, 43 Dementia Counseling Centers will operate in participating municipalities staffed by their already trained personnel.*

Alzheimer Associations have committed to support the Dementia Counseling Centers with regular visits of experienced health professionals, printed material, seminars and events for the first 2 years of operation.

The objectives of the project are:

1. To raise awareness and promote prevention of dementia in the public
2. To decrease the stigma of the disease and organize dementia action groups in local communities
3. To foster independence and autonomy of people with dementia with the use of new technologies
4. To offer intervention programs for people with dementia: Memory Clinic (early diagnosis and effective follow-up), integrated non-pharmacological interventions
5. To organize support groups, psychoeducational interventions and counseling services for carers

Overall, the core aim of the project is to lay the foundations for the creation of dementia-friendly communities in Greece. Our inspiration of a dementia friendly community is a space including friends, neighbors, lay people, shops and businesses, children and young adults and all involved stakeholders that understand and appreciate the condition. It is a place where people with dementia will live as independently as possible and they will be valued, understood and respected.



POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-004

AN EXPLORATION OF DEMENTIA FRIENDLY COMMUNITIES FROM THE PERSPECTIVE OF PERSONS LIVING WITH DEMENTIA

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Abstract:

Objectives: The growing global prevalence of dementia coupled with a shift in public perception from a hopeless disease to the possibility of living well with dementia has led to the formation of dementia friendly communities (DFC). DFCs are a new phenomenon in the United States, with a gap in knowledge on input from people living with dementia. Aim 1: To provide an understanding of living with dementia in the community from the perspective of persons living with dementia through the constructs of interactions and relationships, community engagement, and the experience of stigma. Aim 2: To uncover attributes of a dementia friendly community for the purposes of development and evaluation of communities or initiatives striving to embrace dementia friendly principles.

Methods: This study investigated DFCs from the perspective of persons living with dementia in Western North Carolina. Eighteen older adults ages 65 – 94 with reported dementia or memory loss were recruited from support groups or community organizations. Consent capacity was determined through the Evaluation to Sign Consent Tool. Semi-structured interviews were conducted in participants' homes and analyzed using conventional qualitative content analysis.

Results: Three major themes emerged from the transcribed interviews: (a) transitions in cognition: vulnerable identities, (b) social connections, and (c) engagement in life activities. Personhood was upheld through reframing, resilience, life engagement, gratitude, and social support. Personhood was compromised by loss of identity continuity, sense of burden, health and diagnostic challenges, uncertainty toward the future, waning conversational ability, and stigma. The dynamic experience of living with dementia revealed by participants suggested the following attributes of a DFC: (a) social inclusion, (b) support for role continuity, (c) availability of meaningful and contributory activities, (d) flexible support as cognition transitions, (e) community dementia awareness (to combat stigma), and (f) a supportive diagnostic process. The presence of care partners in the interviews was supportive, and the evaluation to sign consent tool assisted in determination of participant capacity to self-consent. The findings were interpreted through the theoretical frameworks of personhood, the social model of disability, human rights and citizenship, the environmental press model, and transitions theory.

Conclusion: DFC development requires a contextual lens focused on well-being with input from multiple stakeholders including PLWD. Collaboration among community organizations supplemented by local, regional, and national policy supporting flexible service provision and empowerment through cognitive transitions has the potential to provide a strong social network on which to build a DFC.



Dementia friendly communities - Poster

P12-005

DEMENTIA CAFÉ FOR PEOPLE WITH YOUNGER ONSET DEMENTIA AND THEIR FAMILIES USING OLD TRADITIONAL JAPANESE HOUSE

Motoharu Kawai^{1,2}; Setsuko Fuji¹; Noboru Takenaga¹; Ruriko Murota¹; Kyoko Yamane¹; Eiko Saeki¹; Keiko Tamura¹; Takako Harada¹; Chizuko Yamada¹; Junko Koshino¹; Etsuko Kodama¹; Asako Matsumoto¹; Mitsuki Eguchi¹; Sumiko Shiratsuchi¹ and Rie Yoshimoto¹, (1)Alzheimer's Association Japan, Yamaguchi, Japan, (2) Department of Neurology and Clinical Neuroscience, Yamaguchi University Graduate School of Medicine, Ube, Japan

Abstract:

Objective: In Japan, include support for the people with dementia and their caregivers as one of the main measures of "The Comprehensive Strategy to Accelerate Dementia Measures", so called "New Orange Plan" from 2015. The installation of dementia café has been promoted as one of the strategy for the plan. Meanwhile, strengthening measures for people with younger onset dementia is mentioned, but there are few communities where they can spend peacefully. We held a cafe for persons with younger onset dementia and their caregivers, the project was outsourced from Yamaguchi prefecture administration.

Method: We utilized the old traditional Japanese house that are older built more than 100 years (kominka) in the Yabara, Yamaguchi City, Yamaguchi Prefecture. There is the earthen floor(doma) in the place where entered the front door. And the open-timbered high ceiling is left beams made of pillars of the big tree, and left traces of smoked soot, these structures to become a nostalgic feeling. The holding time was 2 hours. Participants were six pairs of people with dementia and their families, and about 40 supporters. Many people with dementia were mild. Supporters were rich in variations including doctors, nurses, administrative staff, nursing care family, and university students. As for the activity contents, while eating drinks such as coffee and tea and sweets, people with dementia and their families relaxed and talked with supporters and each other.

Result: Of the six pairs of people with dementia and their families, five pairs enjoyed until the end time. People with dementia and their families were able to share the communication space and interact with each other, so it was a peaceful atmosphere. One pair left with halfway. In the questionnaire most of the comments were positive.

Conclusion: Our dementia cafe utilizing the kominka can be a good place for people with younger onset dementia and their families. However, it is a future subject to make a friendly place even for those who can not adapt to this holding method.





POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-006

SURVEY ON KNOWLEDGE AND ATTITUDES TOWARD DEMENTIA AMONG TEACHERS IN SEJONG CITY

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Abstract:

Background: To increase awareness of dementia is important to not only residents in community but also students. Students are recognized to play important roles in the future in terms of making the community with better understanding with dementia, because their generation will face with a lot of social issues caused by dementia and the learning from solving the social issues will support them to build better health welfare system and policy for the elderly.

Objective: This research was subjected to teachers working at primary, secondary, high school in Se-jong city. The sample was selected by using sampling with probability proportional size after considering the distribution of primary, secondary, high school based on ratio and suburb. The survey was about awareness of dementia, teachers' interests in dementia and importance of dementia education towards students. The result was analyzed to be utilized for developing and improving educations for prevention of dementia, targeting primary, secondary, high school students in Se-jong city. Also the result will be used to improve awareness of dementia and promote dementia related education.

Method: The research method was the survey which was asking about awareness of dementia. This survey was developed in 2008 by the research team which was specifically research for the rate of prevalence of dementia in the elderly. The survey contains 8 questions about demography (e.g suburb of the school where respondent is working, level of school that respondent is working, type of establishment, level of respondent, gender, experience, age, teaching subject) and 15 questions related to awareness of dementia, interests of dementia. The survey was conducted for about 20 days from October 10, 2017 to October 30, 2017. 396 survey, except not fully filled survey, were used for final analysis and statistic for collected data was analyzed by SPSS Win (ver.22).

Result: The number of female subjects (279 people, 70.5%) was higher than the number of male subjects (117 people, 29.5%). The highest number of people who participated in the research was aged 30-39 years old (131 people, 33.1%), and the subjects in the research worked in primary school (197 people, 49.7%), high school (101 people, 25.5%), and secondary school (98 people, 24.7%). The score for awareness of dementia was average 11.86 ± 1.58 out of total score 15. Percentage of correct answers was average 79.1%. Variables which affect interests of dementia were age, work experience as teachers, knowledge of dementia, access to information of dementia, opportunity of dementia education. Variables which affect level of knowledge of dementia is aged, work experience as teachers, current level, interests in dementia, access to information of dementia, opportunity of dementia education. Variables which affect dementia education subjected to students were level of school, opportunity of dementia education.

Conclusion: The teachers at schools agreed and understand the importance of education and they are willing to attend educations but they were not sure how to educate and who will be the main educators for students in relations to provide quality of education. Dementia education is not included and compulsory in education curriculum in all level of schooling, attending dementia education is not popular. Therefore, it is encourage to promote the participation in dementia education since dementia became major social issue.



POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-007

AN EXPECTED ROLE AND ENSURING CONTINUOUS COMMUNICATION OF THE ASSOCIATION RELATED DEMENTIA AND STAKEHOLDERS GROUPS FROM ADI 32TH CONFERENCE IN JAPAN

Morio Suzuki; **Ms. Naoko Hara***; Kayo Abe and Matsuyo Kamada, Alzheimer's Association Japan, Kyoto, Japan

Abstract:

At the 32th ADI Conference, we presented a panel discussion by five stakeholder groups regarding the need for close cooperation among dementia related stakeholders groups. For subsequent action, we were started continuous communication as the liaison meeting for dementia related stakeholders and supporters -tentative-. We have two primary objectives of meeting. The first, we will work harmoniously to engage in educational activities as a forum conference on disease of dementia -alzheimer's, Lewy Bodies, and so on- or caring -all caregivers, male caregivers, early onset dementia and so on-. The second, we will appeal to people and involved to communicating and maintaining a respectful relationship steadily and slowly with dementia related stakeholder groups - as a person with dementia, as a family caregivers, as a partners - in japan.

We had already met several times after the previous ADI conference, we will meet with regularity for liaison meeting. We will hold on the domestically forum conference within this year, whereat we send a message the sharing action assignments with the inclusion of policy recommendation and demand to government from each group activities about caring for dementia. Furthermore, we will continuous deeply discussion about these assignments on the liaison meeting, provide announcement at any other forum or the portal website from APR. 2018. Therefore, we expect to become a matter of public concern about these disease and caring.

We are expecting to become involved more the related groups and the concerned in our meeting, thus it will be easy to change for the better social systems and service for caring, development of a cure for dementia. It will need for each country or district for future such as these liaison relationship about dementia. People have needed for the personal concerned group about dementia -ex. frontotemporal dementia, bachelor sons carer-, because we have covering a board range of topics of caring for dementia. It is therefore useful for these groups to be associated lobby government with such the dementia related stakeholder groups, we strongly encourage further efforts. This work was supported by The Pharmaceutical Research and Manufacturers of America.



POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-008

PREVENTION OF DEMENTIA THROUGH ACTIVITIES OF THE UNIVERSITY THIRD AGE IN SKOPJE, R. MACEDONIA

Doncho Methodi Donev*, Institute of Social Medicine, Faculty of Medicine SsCyril and Methodius University, Skopje, Macedonia, The former Yugoslav Republic of; Dragan Ljubomir Ilievski Dr., Association of Alzheimer Disease Macedonia, Skopje, Macedonia, The former Yugoslav Republic of; Shekerinka Trajan Ivanovska Prof, Faculty of Economics, International Slavic University, Sveti Nikole, Macedonia, The former Yugoslav Republic of and Hristo Anastas Lovačev M-r, University Third Age, Skopje, Macedonia, The former Yugoslav Republic of

Abstract:

Objective: To present the scope of educational, cultural, working and entertainment activities within the University Third Age in Skopje, R. Macedonia in the period 2012-17.

Method: A retrospective study based on archive materials and documentation with registered activities of the University Third Age in Skopje, R. Macedonia, other relevant sources of information, and a review of the relevant literature.

Result: The Citizen's Association "University Third Age" in Skopje has been established in 1999 with the main aim to create an environment of cooperation, community, learning and exchange of experiences of its members toward reviving the principles of lifelong learning and participation in society through creating opportunities for active and dignified life in the third age.

The number of members of the Association is constantly increasing, especially in the last 5-6 years followed by increasing the affirmation and expansion of its activities. Currently, it has more than 800 members, and about 150 of them are constantly active and involved in realization of the Association's activities.

The Association actively cooperates with the Red Cross of R. Macedonia and the Institute for Social Affairs, with a large number of civic, cultural, artistic and professional organizations, national and international organizations and associations, among them the University of the Third Age in Ljubljana, Slovenia.

In the last six years, the Association has implemented a wide range of activities and participated in realization of several projects. The Association holds its educational lectures every Friday at premises of the Faculty of Philosophy in Skopje. About 40 educational and interactive lectures held annually, mainly in the field of medicine, preventive medicine and healthy life, but also for other issues of interest to people of the third age, such as psychology, philosophy, recreation, sports, science, etc. The Association organizes and realizes annually an average of approximately 20 trips in the country and abroad, as well as the same number of visits to cultural events and of recreational walks. **Table 1** presents more detailed overview of activities in the period 2012-17.





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Table 1. Overview of the activities of the University Third Age in Skopje, R. Macedonia in the period 2012-17

TYPE OF ACTIVITY	REALIZED ACTIVITIES						
	2012	2013	2014	2015	2016	2017	TOTAL
Educational lectures	40	41	37	37	41	40	236
Computer lessons	/	/	/	37	41	42	120
Excursions and trips in Macedonia	19	17	18	19	22	25	120
Excursions and trips abroad	5	5	4	5	6	6	31
Fun and celebrations	7	7	6	8	8	9	45
Visits to cultural events	20	21	24	23	26	28	142
Visits to immobile persons	50	48	54	56	59	59	326
Recreational walks	19	24	20	21	22	29	135
Cooperation with the University Third Age in Ljubljana	2	3	2	3	3	2	15

Conclusion: The broad scope of activities within the University Third Age in Skopje, R. Macedonia proved to be a very suitable form of action among the people at this age as a positive social trend of substituting passivity and depression with an active, meaningful and dignified life in the third age.





POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-009

WHY BUSINESSES AND ORGANISATIONS NEED TO BE MORE DEMENTIA-FRIENDLY

Philippa Tree and **Sarah More***, Alzheimer's Society, London, United Kingdom

Abstract:

'It's not rocket science, it's just customer service plus!' John, living with dementia

This abstract presents why it is crucial for organisations and businesses to become more dementia-friendly and what Alzheimer's Society is doing to encourage this in the UK. We will discuss our Dementia Friendly Business Guide, how it was developed, and how it can be used by all organisations to support them to become more dementia-friendly.

All businesses and organisations can contribute to tackling the social and economic impact of dementia. From retail to housing, utilities to entertainment, finance to transport. All sectors have a part to play.

Often people stop doing the things they enjoy in their local community as their dementia progresses because they are worried about getting the support they need (Alzheimer's Society, 2013). The impact on people's quality of life and implications on their health is huge, not being able to access parts of community life such as shops or pharmacies; but also other aspects of everyday life such as financial services or leisure pursuits.

"I have difficulty recognising money and find it difficult using coins so only use £10 notes and trust people to give me the right change"

Why businesses and organisations matter?

Dementia costs businesses £1.6 billion per year in the UK (CEBR, 2014), and although 89% of employers believe that **dementia will become a bigger issue** for their organisation and their staff (Employers for Carers, 2014) 73% of UK adults surveyed **do not think** that businesses and organisations are geared up to deal with dementia (Alzheimer's Society, 2013).

With the UK statutory retirement age rising, and the number of people with dementia expected to rise to 1 million by 2021, we will see many more people developing dementia or becoming a carer whilst still in employment. Businesses need to future proof their organisations, as consumers want businesses which value their customers. A key benefit to organisations in becoming dementia-friendly is that when a business gets it right for people with dementia, it gets it right for everyone.

The pilot

Ten business pilots helped to inform and develop this guide. These included airports, gas companies, large retailers and banks. An assessment was made on how they support employees, customers or clients in key areas including HR processes/procedures, training and awareness, customer support and physical environments.

Dementia Friendly Business Guide

The findings were made into a Dementia Friendly Business Guide: a guide to support all organisations through advice, best practice case studies and sector specific actions.



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This resource looks at three key areas that can be adopted by any organisation – large or small.

- People:
 - Training and awareness
 - Supporting staff affected by dementia
- Processes
 - Customer and client support
 - Information provision and signposting
- Places
 - Reviewing their physical environment.
 - Community engagement

Defeating dementia won't just happen in a lab or in a care setting, we need a whole societal response. By developing an understanding of the condition, businesses can make a huge difference to people living with dementia and their quality of life.

Download a free copy of the Dementia Friendly Business Guide - alzheimers.org.uk/business



POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-010

EVIDENCE-BASED POLICY MAKING AND CAPACITY PLANNING FOR COMMUNITY-BASED DEMENTIA HEALTHCARE SERVICES USING AGENT-BASED SIMULATION AND ADMINISTRATIVE HEALTH CARE DATABASES IN ONTARIO, CANADA

Tannaz Mahootchi¹; **Mrs. Natalie Irene Warrick**^{2,3}; Danielle Shawcross¹; Ali Vahit Esensoy¹ and Dallas Seitz^{3,4,5}, (1)Strategic Analytics, Cancer Care Ontario, Toronto, ON, Canada, (2)Ihpme, University of Toronto, Toronto, ON, Canada, (3)Integrated Care and Quality Initiatives, Cancer Care Ontario, Toronto, ON, Canada, (4)Geriatric Psychiatry, Providence Care Hospital, Kingston, ON, Canada, (5)Queens, Institute for Clinical Evaluative Sciences, Kingston, ON, Canada

Abstract:

Objective: Prevalence of dementia in Ontario is expected to reach 220,000 by 2020, with 65% of this population living in the community. Keeping persons living with dementia (PLwD) adequately supported at home requires expansion of community services capacity and innovative models of care. The Dementia Capacity Planning Project (2015 – 2018) evaluated the impact of planned implementation of evidence-based interventions and health service delivery policy options at the local level using analytical and simulation models.

Method: A validated diagnostic algorithm and multiple administrative healthcare databases were used to identify PLwD in Ontario between 2010 and 2015. Person-level data were used to establish personal and clinical attributes of this population, follow their health service usage longitudinally, and characterize transitions among care settings. The most effective interventions among eleven topics relating to care and management of community-dwelling PLwD were selected by investigating the literature via scoping review. Scholarly articles were identified using electronic databases (MEDLINE and PsycINFO) and GRADE applied to assess evidence strength. An agent-based simulation model was developed using the results of analyses on PLwD data and evidence from literature. The model was used to estimate the capacity requirements, the resulting changes to PLwD transitions from the community, and their health service utilization for the planned implementation of care-partner education and supports and adult day programs for PLwD between 2014 and 2020.

Result: We screened 468 abstracts, 152 full-text articles and included sixty-one studies published between 1985 and 2016 representing meta-analyses, systematic reviews, randomized clinical trials and cohort studies. Our scoping review identified only four community-based interventions: adult day programs, care partner education, comprehensive community-based care, and, dementia case management reported sufficient evidence to consider including in scenario modelling for dementia capacity planning. Community-dwelling persons with dementia increased to 106,427 individuals over the period of 2010 to 2015 (+30%) and by 2020 are projected to increase to 142,557 (38%) over 2015. If no programmatic interventions are applied, by 2020 the total number of PLwD awaiting their first LTC placement will increase by 80%, over 2015 estimates. Alternatively, if education and support programs for care-partners were implemented, we estimate a 32-percentage point reduction to 48%. This is a prominent effect, given that PLwD awaiting LTC placement use significantly more healthcare resources, including hospitalizations, emergency department visits, and homecare services, than those who are not. To realize the effects of such an intervention, Ontario needs to build capacity for 71,507 monthly counselling hours and provide monthly support groups for at least 34,304 persons by 2020.

Conclusion: Simulation models and other advanced analytics approaches calibrated at the local level were utilized to understand future demands and provide insights on the potential effects of programmatic interventions on the healthcare system while sizing the capacity needs at the system level. System-level impact of implementing various scenarios informed future planning of Ontario's Dementia strategy and health service delivery at the regional level.



Dementia friendly communities - Poster

P12-011

A CALL FOR AGE-FRIENDLY COMMUNITIES: EVALUATING THE IMPLEMENTATION AND SUSTAINABILITY OF AN INTERGENERATIONAL LEARNING PROGRAM FOR AUSTRALIANS LIVING WITH DEMENTIA

Xanthe A Golenko¹;Katrina Radford¹;Nerina Vecchio²;Janna Anneke Fitzgerald³ and **Ashley Cully**^{*4}, (1) Department of International Business and Asian Studies, Griffith University, Gold Coast, Australia, (2)Department of Accounting Finance and Economics, Griffith University, Gold Coast, Australia, (3)Griffith University, Gold Coast, QLD, Australia, (4)Griffith University, Gold Coast, Australia

Abstract:

Objective: Intergenerational learning programs are planned ongoing activities which purposefully bring together different generations to share experiences that are mutually beneficial. The psychological benefits for both children and older adults are well documented, however little is known about the operationalisation and implementation of sustainable intergenerational learning programs. This research evaluates an intergenerational learning program being implemented within two modes of care: *Shared Campus mode*, where an aged residential care facility is co-located with a childcare centre; and *Visiting Campus mode*, where child care and aged respite day-care centres are located separately and one group of care recipients is transported to the other site.

Method: The research is being conducted across four locations within Queensland and New South Wales among older adults living with dementia and children aged three to five years. The intergenerational learning program involves sixteen one-hour sessions of shared activities specifically designed to enhance engagement between generations. Using a mixed methods case control design, the study incorporates survey, video ethnographic, and interview data to evaluate outcomes and compare findings with matched controls. The outcome measures focus on three key areas: 1) health and economic impacts on participants, their families and care providers, 2) educational implications in terms of developing an evidence-based intergenerational pedagogy and adding to eldergogy, and 3) workforce implications in terms of developing a new career structure that combines aged care and child care qualifications.

Results: Preliminary research into the feasibility of intergenerational care programs being implemented in Australia indicates that legislative requirements need to be taken into consideration, however potential barriers can be overcome with careful planning and consultation. In addition, a willingness to pay study revealed that there is demand for intergenerational care and parents and carers are more likely to take up intergenerational care compared to the status quo.

Conclusion: Findings from this research will inform the development of operational guidelines that can be used in the planning and delivery of sustainable intergenerational learning programs within the Australian setting. Findings will also inform the development of policy guidelines that support and promote building age-friendly communities.





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Dementia friendly communities - Poster

P12-012

IMPLEMENTING POLICY AND SYSTEM CHANGE TO MAKE OFFERING CLINICAL RESEARCH A STANDARD PART OF DEMENTIA CARE PATHWAYS

Piers M Kotting^{*}, Medical School, University of Exeter, Exeter, United Kingdom and Adam Smith, Institute of Neurology, University College London, London, United Kingdom

Abstract:

In 2012 the UK Prime Minister launched the '*Challenge on Dementia*' to stimulate policy and system change to deliver "major improvements in dementia care and research." The *Challenge* noted "people with dementia and their carers are not routinely offered the opportunity to participate in high-quality research". The National Institute for Health Research (NIHR) National Director for Dementia Research was tasked with delivering the necessary policy and system change to create a nationally consistent system to enable them to do so, should they wish.

Since 2012 the NIHR has delivered a programme of activities aimed at influencing policy and delivering system change to ensure people with dementia and their carers are routinely offered the opportunity to participate in research as part of normal care practice. A central tenet across both strands has been wide stakeholder engagement, with people affected by dementia and the main third sector organisations at the heart of the programme alongside researchers, clinicians and the key public sector organisations.

The policy strand has incrementally increased the scope and prominence of research in relevant policy, from inclusion of research in the Royal College memory clinic accreditation process, to inclusion of research recruitment objectives in the government's Dementia 2020 strategy and in NHS England's 'Dementia: Good care planning guidance for commissioners'; and subsequently a target for the proportion of people with dementia being offered research opportunities in the Dementia 2020 policy implementation plan.

Alongside, the system change strand has involved the design and development of a new national public engagement and research recruitment service that was launched in 2015: Join Dementia Research, the implementation of which is supported by national and regional change programmes, and the NHS Innovation Accelerator Programme.

In three years 32,000 people have registered with the service, 80% of whom say it has increased their awareness of research. It is promoted in an estimated 70% of memory services. It has had a direct and indirect impact on research activity with over 30,000 people recruited to dementia studies each year since the service launched, up from 13,000 a year in the preceding 4 years.



Dementia friendly communities - Poster

P12-013

SALZBURG GLOBAL STATEMENT FOR A DEMENTIA-FRIENDLY WORLD

Angela M Lunde*, Alzheimer's disease Research, Mayo Clinic, Rochester, MN; **Olivier Constant**, Flanders Centre of Expertise on Dementia, Antwerp, Belgium; **Ms. Emily A Farah-Miller***, Metropolitan Area Agency on Aging, St. Paul, MN; **Joan Griffin**, Health Sciences Research, Mayo Clinic, Rochester, MN; **Amalia Fonk-Utomo**, Communication, Alzheimer's Indonesia, Groningen, Netherlands and **Omini Oden**, Nigerian Television Authority, Abuja, Nigeria

Abstract: Coinciding with increasing life expectancy worldwide is the increase in the number of people with dementia. Although the rising prevalence rates vary by country and region, the World Health Organization (WHO) indicates the prevalence of persons living with dementia will triple in the next 30 years, *from 50 million in 2017 to 152 million by 2050*. This unprecedented reality has already brought with it major challenges, yet, at the same time it offers opportunities to think globally, innovatively, and outside the traditional medical model for solutions.

A call to action to create a dementia-friendly world was the outcome of the 587th Salzburg Global Seminar in November 2017 called 'Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities'. The actions expressed in this statement are shared by the fellows of the Seminar and represent 15 countries including people living with dementia and family caregivers. The fellows identified the following key principles necessary for a global solution toward a dementia friendly world and a better life for those impacted by dementia.

- **Choose and use words and language thoughtfully.** Words influence attitudes and behaviors that can either enable and empower, or further marginalize and stigmatize those living with dementia. Using appropriate language in all forms of communication is a number one priority.
- **Recognize people with dementia as the experts they are.** Talk openly and listen to people living with dementia. Many are able to advocate for their own needs and the needs of those who are unable to speak for themselves. People with dementia can often educate the public and inform policy makers, health care providers, researchers, and the media.
- **See a person first, not a disease or label.** A dementia-friendly world focuses on the person, not the diagnosis or symptoms. The focus is to understand the person including their background, values and preferences, as well as the persons' abilities, strengths, and potential.
- **Act locally, share globally.** In the same way that the medical community shares knowledge and progress, dementia –friendly communities must collaborate, disseminate best practices, and work to translate knowledge and resources across divides.
- **Evaluate dementia-friendly efforts.** Initiatives that can demonstrate success in outcomes that matter most to people living with dementia are what matter most. In addition, metrics around economic impact, community stigma, psycho-social and/or health status will support long-term sustainability.
- **Advocate for a timely diagnosis.** An accurate and timely diagnosis is a both a human right and a personal choice, promoting shared decision making between the person with dementia, their healthcare team and the family. Healthcare professionals must ensure the burden of dementia isn't magnified by their own language and attitudes.
- **Accept that a dementia-friendly community is an ongoing process.** Rather than a community arriving at a goal of being dementia friendly, it should be seen as a continuous process of 'working toward' dementia-friendly.
- **Promote the message of empowerment as part of your narrative.** Across the globe people living with dementia share that they want to feel understood, acknowledged, respected, included, and safe. They want to be enabled to live the best life possible with a sense of purpose, enjoyment and belonging. Find examples that illustrate these global values and share them widely.



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P12-013

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POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-014

EVERYONE HAS A RIGHT TO CULTURE AND LEISURE - A DEMENTIA-FRIENDLY APPROACH

Emma Bould Ms¹; Sara-Jane Little¹ and **Sally Copley**², (1)Campaigns and Partnerships, Alzheimer's Society, London, United Kingdom, (2)Policy, Campaigns and Partnership, Alzheimers Society, London, United Kingdom

Abstract:

69% of people with dementia surveyed by Alzheimer's Society said the main reason they stop going out is lack of confidence. With the associated problems of isolation and depression for those living with dementia, access to relevant and meaningful activities is crucial to mental and emotional well-being.

Culture and entertainment have a powerful effect on the well-being of people living with dementia and their families. Participatory activities decrease social isolation and increase social engagement, impacting on cognitive and emotional stimulation, self-esteem and episodic memory.

Everyone is entitled to participate in cultural and entertainment activities as a basic human right, supported by the Universal Declaration of Human Rights (articles 24 & 27) and the UK Equality Act 2010. This doesn't change with a dementia diagnosis.

This session explores how advocates in the UK are working to support the right to access culture and leisure activities, and how a dementia-friendly approach to engage the cultural and heritage sectors can be adopted internationally.

How can establishments become more dementia-friendly?

Alzheimer's Society has developed two new guides - 'Rethinking Heritage: A guide to help make your site more dementia-friendly' and 'Dementia Friendly Screenings: A guide for cinemas'. These guides raise awareness of dementia, and encourage organisations to work towards becoming dementia-friendly by providing clear recommendations and best practice case studies. Cinemas and heritage sites are provided with the tools and support they need, but nothing is more valuable than listening to people living with dementia.

Heritage: Visiting a heritage site is one of the top activities people with dementia want to do in the UK, and forms part of the international tourist offer. Heritage sites should look to become dementia-friendly by firstly providing a welcoming space. We recommend employees understand more about dementia through the Dementia Friends initiative, and organisations ensure they have plenty of staff to provide a supportive and reassuring environment. Clear signage will make a difference and help people navigate with confidence. In addition, organisations should advertise support available in easy to read large print information leaflets or accessibility guides, made available online and through local services to raise awareness.

Cinemas... A growing number of cinemas across the UK are offering dementia-friendly film screenings, creating social spaces that are accessible and welcoming. Knowing the audience is crucial to get this right, and certain types of films such as musicals are particularly engaging because the brain processes music differently to other functions. It's important to consider the environment, a pitch black room can be intimidating and it is more difficult to identify exits and toilet signs. Sound also needs careful consideration, as raising the volume too high can be stressful, but many older people with dementia may also be hard of hearing.

Central to our communities, cultural venues and entertainment activities have a major role to play in welcoming and accommodating people with dementia and their carers. As we all become more aware of the significant impact of dementia on society, there is much more that heritage and cinema industries can, and should, be doing. This session will share the UK experiences of driving the cultural and heritage sectors to put the rights and needs of people living with dementia first.

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Dementia friendly communities - Poster

P12-015

CREATING THE MUSEUM-CENTRED DEMENTIA-FRIENDLY COMMUNITY TO ENHANCE SOCIAL ENGAGEMENT OF PEOPLE LIVING WITH DEMENTIA

Zhong-Han Lee¹; Hui-Ya Lin¹; Chun-Chun Chen¹; **Dr. Chien-Liang Liu²** and Sheng-Jean Huang², (1)Zhongzheng District Health Center, Taipei City, Taiwan, (2)Taipei City Hospital Heping Fuyou Branch, Taipei, Taiwan

Abstract:

Objective: With the increment of the human longevity, there are more people living with dementia, causing the need for dementia-friendly communities is urgent. The Museum of Modern Art (MoMA) in New York had developed the project "Meet Me at MoMA", inviting people living with dementia to visit MoMA to provide them opportunities for social engagement. There are 18 museums located in our community. We wanted to integrate museums with other resources, creating the museum-centered dementia-friendly community, with social engagement aspect for our major evaluation.

Method: We referred to the social engagement aspect of the dementia-friendly communities checklists issued by Dementia Australia and developed 3 strategies to reach the goal.

1. **Recognizing contributions to the community:** We collaborated with several museums, which can easily be reached by public transportation with lowered ticket prices for people living with dementia and care partners, whom we invited to see the exhibitions, reminding them of their long-term memory. By using clay, building blocks, cardboard and other materials for art, they created compelling visual content of the most impressive scene of their memory. Though displaying their works and explaining the underlying stories, the public recognized the past and ongoing contributions of people living with dementia to the community.
2. **Placing the hoping tree:** We placed the hoping tree around the activities for dementia held by the museums and community. People living with dementia and care partners can write down their opinions and feedbacks on pieces of paper and stuck on the hoping tree. With this convenient way to express their thoughts, we refined the strategies according to their ideas to provide best service for them.
3. **Building museum-centered caring network:** We provided museums and shops and clinics around the museums staff training. With staff training, the personnel were aware of the needs of people with dementia and tailored their services to support people living with dementia and care partners. In addition, we held speeches and interacting campaigns about dementia, raising the dementia awareness of the community resident around the museums. We also held memory café around the museums, providing a relaxed place for the care partners to relieve the pressure of care. With this strategy, residents of the community and a variety of organizations around the museum became dementia-friendly, forming the museum-centered caring network.

We utilized the social engagement index, adapted from the dementia-friendly communities checklists issued by Dementia Australia, to evaluate the efficacy of the intervention.





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Result: We have collaborated with 3 museums. There were 46 people living with dementia and care partners attended museum activities. We collected 172 opinions and refined our strategies. There were 176 employees completing the training course. In addition to the museums, we recruited 25 shops and clinics around the museums to become dementia-friendly organizations. There were 566 people attended the speeches and interacting campaigns. We held memory café activities for 6 times. All the items of social engagement aspect of dementia-friendly communities checklists were fulfilled. The average increment of social engagement index is 4.1 (n=46, $P<0.05$).

Conclusion: There are more than 500 museums in Taiwan. Our success model can implement in other areas of Taiwan, creating a better place for people living with dementia and care partners.





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Dementia friendly communities - Poster

P12-016

COMMON PATHWAYS AND PREDICTORS OF THE TRAJECTORIES OF PERSONS WITH DEMENTIA THROUGH LONG-TERM CARE OVER TIME - A WESTERN CANADIAN STUDY

Dr. Denise Suzanne Cloutier*, Geography, University of Victoria, Victoria, BC, Canada and Margaret Penning, Sociology, University of Victoria, Victoria, BC, Canada

Abstract:

Objective: The purpose of this research is to explore the most common service use trajectories over time, and their predictors among a sample of long-term care clients with evidence of dementia.

Method: This study uses latent transition analysis (LTA) to understand service use patterns and predictors for clients with dementia, drawing on four years of administrative data for n=3541 individual clients aged 65+. These clients received care in a populous health region in British Columbia, Canada between January 1, 2008 and July 31, 2012.

Result: Four categories of client experiences emerged from the analyses: continuous home care, intermittent home care, residential care and a mortality class. The most important predictors of these patterns of use were: age, marital status, living alone, income, chronic conditions, ADL scores, falls, cognitive performance and behavioural issues in the first year of service. These characteristics became less significant for subsequent years in care.

Conclusion: Our results reveal that differential patterns in service use over time depend heavily on where people start in the care system. These findings have implications for health care policy, planning and decision-making related to the care of persons with dementia.





Dementia friendly communities - Poster

P12-017

OUT-OF-POCKET COSTS INCURRED BY FAMILY CAREGIVERS OF PERSONS LIVING WITH DEMENTIA ON CANADIAN HOMECARE: A SCOPING REVIEW

Mr. Husayn Marani^{*}, University of Toronto, Institute of Health Policy, Management and Evaluation, Toronto, ON, Canada

Abstract:

Objective: The prevalence and cost of dementia are rising in Canada. However, what these costs are and by whom they are shouldered is largely unclear. This scoping review summarizes evidence on out-of-pocket costs incurred specifically by family caregivers of persons living with dementia (PLWD) in Canada and their policy implications.

Method: To capture the multidisciplinary nature of dementia studies, four databases (Medline, ProQuest, AMED and Econlit) were searched for English-language articles published between 2000-2017, including scholarly theoretical/empirical papers and grey literature (for example, news articles, government reports, and opinion pieces). Inclusion criteria were: 1) Canadian context; 2) costs must be out-of-pocket, which, by definition, excludes reimbursable/insured costs and opportunity costs; and 3) dementia (or encompassed disease) must be the primary morbidity discussed. Articles meeting these criteria were thematically analyzed by hand.

Result: Overall, this search yielded 418 results. Excluding duplicates and results that did not meet the inclusion criteria yielded 20 results. In summary, the literature demonstrates that family caregivers shoulder the majority of direct non-medical and indirect costs. Severity of dementia is a key predictor of these costs for PLWD in both institutional (long-term) and community (home) care settings. To decrease the financial burden of dementia care on the health system, many provincial governments have implemented aging-at-home strategies to shift costs from historically costly institutional care to community care. In doing so, this has imposed a greater financial burden on family caregivers. Evidence is emerging that family caregivers of PLWD will become significant consumers of the health system as a result of these financial stressors.

Conclusion: As the prevalence of dementia rises in Canada, there is growing interest among policy makers and interest groups in financial risk protection of family caregivers of PLWD. With the recent passing of Bill C-233 (Canada's national dementia strategy), these results are timely and highlight important knowledge gaps and policy implications.





POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-018

THE EFFECTS OF MACAU DEMENTIA POLICY ON THE DEMENTIA DIAGNOSIS RATE IN MACAU

Dr. Lek Long Lo*, Geriatrics, Macau Health bureau, Macau, China and Cheong U Kuok, Macau Health Bureau, Macau, China

Abstract:

Objective: To evaluate the effects of Macau Dementia Policy on the Dementia diagnosis rate.

Method: Dementia diagnosis rate is one of the key performance indicators of Dementia services. Macau Dementia policy was launched in Sept 2016 to increase public awareness and streamline the Dementia services in Macau. Measures included: 1) implement city-wide public education with professional bodies and non-government organizations, 2) simplify cognitive assessment and referral process, and 3) provide integrated post-diagnosis health and social care. We evaluated the diagnosis rate of Dementia before and after the launch of Macau Dementia policy. Estimated number of people with dementia was calculated as 6% of the citizens aged 65 year-old or above. The number of confirmed cases of dementia was extracted from Macau Dementia Registry at the end of 2016 and 2017 respectively.

Result: There were 63400 elderly at the end of 2016, accounting for 9.8% of Macau population. The number of cognitive assessment by Macau Health Bureau increased from 552 in 2016 to 1415 in 2017. The number of confirmed cases of dementia increased from 1603 to 1900 in one year. The diagnosis rate of Dementia increased from 42.1% in 2016 to 49.9% in 2017.

Conclusion: The implementation of Dementia policy increased the quality of service and diagnosis rate of Dementia in Macau.





Dementia friendly communities - Poster

P12-019

THE COMMUNITY-BASED SUPPORT CENTRE FOR DEMENTIA CARE IN TAIWAN SPEED UP THE DIAGNOSIS OF DEMENTIA: YILAN EXPERIENCE

Ping Huang Tsai¹, Neurology, National Yang-Ming University Hospital, Yilan City, Taiwan; **Nai-Wei Hsu**, Community Medicine, National Yang-Ming University Hospital, Yilan City, Taiwan; **Cheng-Yu Chang**, Nursing, National Yang-Ming University Hospital, Yilan City, Taiwan and **Hsueh-Ping Chiang**, Medical Administrative Office, National Yang-Ming University Hospital, Yilan City, Taiwan

Abstract:

Objective: Dementia refers to a broad category of brain diseases that present as a progressive decline in cognitive function beyond that expected from normal aging. In Taiwan, “10-year long-term care 2.0 plan” was passed on September 29, 2016, which expanding coverage to include people over the age of 50 with dementia. Under this policy, twenty Community-based Support Centers for Dementia Care were established in 2017 to speed up the diagnosis of dementia by integrated management. In Yilan, the center was operated by National Yang Ming University Hospital (NYMUH). Before running the Community-based Support Centers for Dementia Care in Yilan, NYMUH provided one-stop memory clinical for the diagnosis of dementia since 2014.

Method: Community-based Support Centers for Dementia Care in Yilan provided dementia education to volunteers in communities, staffs in insurance companies and teachers in elementary schools, but not performed the dementia screening in populations, which may cause unnecessary stress in communities.

Result: Before Community-based Support Center for Dementia Care in Yilan, the diagnosis number of dementia was 14.4 ± 9.3 per month. After the center, the diagnosis number of dementia was 33.8 ± 9.8 per month. The p-value was significant (0.000) by Mann-Whitney U test.

Conclusion: Community-based Support Centers for Dementia Care in Yilan speeds up the diagnosis rate of dementia by the dementia education promotion but not dementia screening.





POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-020

MACAU DEMENTIA POLICY: BUILDING DEMENTIA FRIENDLY COMMUNITY IN A CHINESE CONTEXT

Iek Long LO Dr*, Health Bureau, Macau, Macao

Abstract:

Macau Government has launched Macau Dementia Policy for prevention and control of dementia on September 2016, which had gained the recognition of ADI that recognizes Macau as the world's 27th region for the implementation of dementia policy.

Older persons accounted for 9.8% of the population in Macau in 2016. The study shows that there are 4.97% of older persons who have early symptoms of dementia. According to ADI, there are about 4000 older persons with dementia in Macau. People with dementia often have early forgetfulness and lose short-term memory, time and place disorientation, but still remaining the capacity for self-caring in daily living what can be often misunderstood as a normal ageing process by family or friends in a traditional Chinese culture in Macau.

Macau Government has been very concerned with the medical and social services needs for older people with dementia and the inclusion of prevention and control of dementia in the Macau Government's policy have addressed for seven consecutive years. In 2016, Macau Government integrated the contents of the first five years development plan. In the framework of the policy for the old-age security mechanism of the Macau Government, a blueprint for the planning system for the ten years of gerontology in Macau was established in 2016 (2016-2025). Dr. Alexis Tam, Secretary for Social and Cultural Affairs of Macau Government, announced the formal implementation of the Macau Dementia Policy on 21st September 2016, and hoped that through the government departments, NGOs and social service facilities the work together to develop a synergistic effect of multi-professionals, cross-institutes, cross-regional cooperation. Covering the care for the needs of older persons with dementia and their families/ caregivers, the policy would build a seamless network of medical and social services to achieve "Early prevention, early detection, early diagnosis, early treatment and early support".

Health Bureau has established the "Dementia Working Group", which is following initiatives such as Dementia Friends plan with the Alzheimer's Society UK and Plymouth City, a positive response to this year world dementia month theme [Forget-me-not], planning to carry out Dementia Friends activities to increase the public awareness of dementia as well as to reduce the negative labeling and the stigma of dementia.

In 2016, Health Bureau and Social Welfare Bureau co-operate creating Dementia Medical Center to integrate medical and social services to provide seamless diagnosis, treatment, education, training and community services for people with dementia. Dementia Medical Center forms a network with seven Health Centers throughout Macau. Any Macau resident, suspected of suffering from dementia, can be assessed of cognitive function and be referred to the Dementia Medical Center for the follow-up. After the diagnosis, the treatment and the follow-up program will be scheduled, older people with dementia will be taken care in a Health Center. At the same time, the community care support services are assured by Social Welfare Bureau providing services to the older persons with disabilities including dementia patients through the Home Care and Support Service, the Day Care Centers for the Older People, the nursing homes and the carers' Home, community and inpatient care, rehabilitation and support services.

Macau Dementia Policy promotes traditional Chinese culture care, and build up Macau dementia friendly community.



Dementia friendly communities - Poster

P12-022

PATHWAYS TO DEVELOP A DEMENTIA FRIENDLY COMMUNITY IN KERALA, INDIA

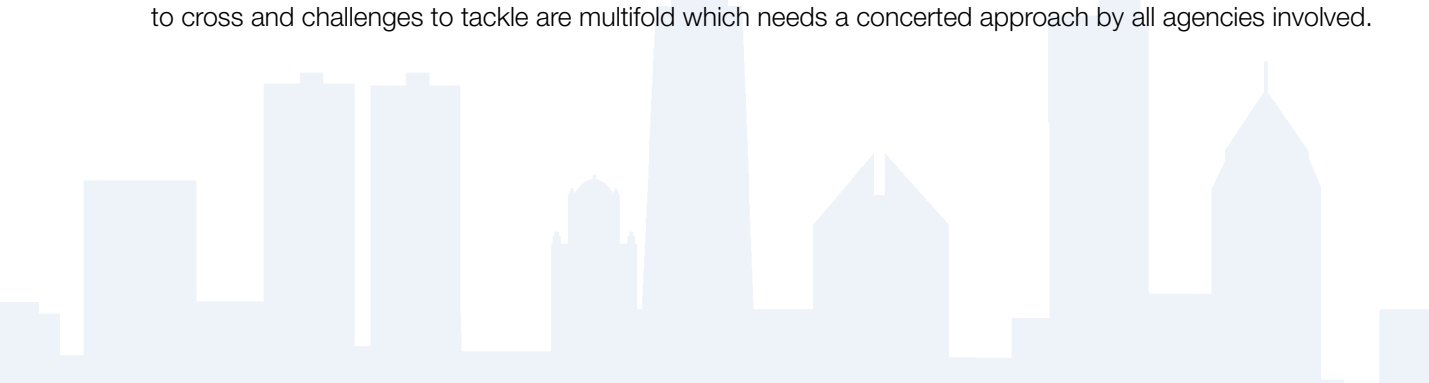
Shaji Sukumaran*, President, Alzheimer's and Related Disorders Society of India (ARDSI), Perumbavoor, Ernakulam District, Kerala, India and Sudhir Kumar CT, Research Development centre, ARDSI-Cochin Chapter, Cochin, Kerala, India

Abstract:

Dementia is emerging as a significant health problem in India along with the demographic transition. It has been estimated that 4.4 million people are affected with dementia in the country. Kerala is the southernmost state of India, with a population of over 34 million. When compared to many other states Kerala is known for its better social development indicators and efficient health care delivery. Hence the implications of demographic transition towards aging are much more marked in the state. Many developments in dementia specific services in India originated in Kerala.

The paper discusses the evolution of dementia care services in India with a specific focus on Kerala and will explore the challenges associated with developing a dementia friendly community in low and middle income countries. The paper also proposes pragmatic pathways to develop dementia friendly communities using a collaborative approach between governmental and non- governmental agencies.

Alzheimer's and Related Disorder's Society of India (ARDSI) began functioning in Kerala in 1992 when awareness regarding the existence of dementia was very low even among the health care professionals; and dementia specific services were non-existent. Epidemiological research conducted by ARDSI at different sites confirmed the presence of dementia in the community as elsewhere. Community based rehabilitation projects initiated by the organization provided a model for care in low and middle income countries. Alzheimer's Disease International conference held in Cochin in 1998 imparted momentum for the activities and 10/66 Dementia Research group was formed as an outcome which paved the way for initiating dementia research in developing countries. Since then a series of activities which included development of services, training programmes for caregivers and professionals, support groups for caregivers, programmes for awareness and advocacy were initiated in the country. Service developments also consisted of developing day care, respite care, domiciliary care, memory clinics and institutional care for people with dementia. ARDSI, through its chapters in various parts of the country motivated various groups of people to create awareness and promoted development of services across India. Dementia India Report (2010) became a milestone which could influence policy makers and governmental agencies. Kerala State initiative for Dementia (KSID), is a path breaking pilot project by Government of Kerala. Training programmes sponsored by National Institute of Social Defense contribute to the development of trained manpower to care for people with dementia. Vayo Mithram (Elder Friendly) project of Kerala Social Security Mission; District Mental Health Programme, Indian Medical Association's wing for Care of the Elderly - all contribute to the welfare of the elderly. Many non- governmental and private agencies are actively engaged in the field. There has been a perceptible and qualitative change in the level of awareness about dementia and development of dementia specific services. Although there are several positive changes in this area the barriers to cross and challenges to tackle are multifold which needs a concerted approach by all agencies involved.





POSTER ABSTRACTS

Dementia friendly communities - Poster

P12-023

10 MILLION DEMENTIA SUPPORTERS TODAY: WHAT WE'VE DONE AND WHAT WE'LL DO NEXT

Ms. Noriyo Washizu*, Alzheimer's Association Japan, Kyoto, Japan

Abstract:

Japan is the most ageing society in the world and in 2017 28% of the population was 65 or over. The number of people living with dementia is 4.62 million and the number of people with mild cognitive impairment was 4 million in 2012. These numbers will keep increasing along with the development of the ageing society.

This situation had been predicted and we started the preparation from the late 1980's, such as instituting the elderly services provision, long term care insurance, and raising awareness of care and prevention, etc. "Dementia Supporter Caravan" is one of these provisions and it aims to build a dementia friendly society.

As we all know, the social security, medical care, and social welfare are fundamental but by themselves "*living well with dementia*" cannot be realized. Understanding and support by everyone in the community, not only by professionals, are necessary for living well with dementia. The Dementia Supporter Caravan campaign started in 2005 and has been contributing to increasing social awareness of dementia and to constructing a framework for the super ageing society along with other policies and approaches. The number of supporters reached almost 10 million by the end of 2017. Now we need to review what the campaign has achieved. How are they acting in the communities? What kind of difference did they make in the communities? What kind of challenges do we have in the campaign? Then we need to look at what we should plan for the future.

To share the progress and perspective of the dementia supporter campaign along with 30 years of approaches dealing with an ageing society and dementia in Japan will benefit us as well as the countries which are expected to face an aging society in the future.





POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-001

RE-HUMANIZING DEMENTIA RESEARCH ON PEOPLE LIKE ME, *WITH ME*: ADDING RIGOROUS QUALITATIVE METHODS TO DISCOVER NEW TRUTHS

Dr. Mary L. Radnofsky Ph.D., Once Human, Forever Human, Alexandria, VA

Abstract:

In the quest to prevent and cure diseases that cause dementia, most scientists use quantitative methodologies; brain researchers simplify human characteristics into numeric variables and run statistics, then analyze results. But such reductionism strips each characteristic of its inherent human complexity, failing to capture underlying truths that exist in those of us living with dementia.

I'm a former qualitative researcher and professor living with dementia, so there's a lot I can tell you about how my brain works, though not on a Likert scale. It is vital to re-humanize brain research by studying us – *with us* – to discover theories that explain the degenerative brain diseases we know from the inside.

In this session, I present three qualitative research models that can be adapted to family, residential care, and independent environments.

The most complex system known is the human brain. It is not limited to a physical existence in the head, but boundlessly extends into the lifeblood and body of its host, into the minds of other people and all living things; it delves into the subconscious, dreams, altered states of being, and non-corporeal hypotheticals; it reaches across space, throughout time, and beyond.

Such a system, by its very nature, cannot accurately be evaluated with a single method, for it holds not only human Empirical and Logical Truths (facts consistent with Nature, or mathematically contingent on known claims) but also the more elusive Ethical Truths (those consistent with moral standards), and Metaphysical Truths (nuanced, highly-complex, difficult-to-articulate beliefs that cannot be tested against pre-established norms).

By incorporating qualitative methods (not supplanting the quantitative), brain researchers can include people with dementia in the design, practice, and analysis of research, since we think differently about ourselves and see the world in ways we never did before.

Understanding such differences is key to investigating the lived experience of dementia. Our brains seamlessly interweave visual, olfactory, auditory, tactile, and gustatory perceptions into knowledge, beliefs, norms, and practices, which cannot be reduced to isolated, simplistic variables and understood. Instead, the complexity of each person, perception, and subtle interactions between them must be studied in natural social settings.

I've used participant-observer methods in qualitative research since the 1980s to analyze evolving relationships and multiple realities both in traditional and non-traditional cultures. This session will provide participants three models of qualitative research that are able to reveal truths about the culture and subcultures of dementia, that can help us discover new theories to explain why some people live well despite the condition, and that can improve our understanding of human reactions to dementia, both from outside and inside the lived experience.

In other words, to best research us, *include us* – from the beginning.



POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-002

PREDICTORS OF INVOLVEMENT, SELF-PERCEIVED PRESSURE, PERCEIVED ROLE AND SATISFACTION OF FAMILY CARERS OF PEOPLE WITH DEMENTIA IN LONG-TERM CARE HOMES

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Abstract:

Objective: INTRODUCTION The demand on long-term care (LTC) homes will rise over the coming years as a result of the growing number of people with dementia worldwide. Quality of care in LTC homes must be assured and, often, improved. In the past three decades, there has been considerable attention for the involvement of family carers of people with dementia in LTC homes. After a person with dementia moves to an LTC home, family carers usually remain involved and play an active part in the care for their relative. Involvement of family carers in LTC homes contributes to person-centered care, which affects the person with dementia positively (and in some cases also the family carer and care staff), and thus quality of care. It is important to study the involvement of family carers in LTC homes, because research has shown that their involvement might have positive as well as negative effects on their psychological wellbeing.

AIM To study 1) how family carers are involved in LTC homes, 2) what elements (of LTC homes, care staff, residents and family carers and type of activities) contribute to self-perceived pressure, perceived role, involvement and satisfaction (with LTC homes) of family carers.

Method: The Living Arrangements for people with Dementia (LAD-)study has been designed to monitor developments in the care in Dutch LTC homes and to study effects on residents, family carers and care staff. The LAD-study was first carried out in 2008 and is repeated every two/three years. Since the second measurement cycle, family carers complete a questionnaire about, amongst other things, their involvement and psychological wellbeing. Care staff and managers additionally provide information about family involvement from their perspective.

Result: Three quarters of managers in LTC homes stated that their care philosophy is that family carers are encouraged to carry out activities with and tasks for their family member and other residents. Within teams of care workers, 48% experienced ambiguity about the care philosophy regarding family involvement. Family carers were on average 5.3 hours per week present in the LTC home. Elements that predicted more time spent in the LTC home were: being a spouse of the person with dementia and experiencing more self-perceived pressure. Several activities that family carers carried out (helping with meals, listening to music/singing and watching TV) were associated with more time spent in the LTC home. Talking with the person with dementia during the visit predicted less involvement. Furthermore, we found that family carers who experienced a greater role in the care for their loved one were more satisfied with the LTC home and perceived less pressure.

Conclusion: Family carers that carry out meaningful activities during their visits spent more time in the LTC home. To experience that you have a role in the care of your loved one with dementia has several positive effects, such as experiencing less self-perceived pressure. Care staff can support family carers by discussing which activities they might best carry out during their visits. Furthermore, care staff should be open to the involvement of family carers in the care of their loved one and encourage it because of the positive effects this yields. Findings furthermore underline the importance of not only formulating a care philosophy, but also paying attention to how to incorporate this in day to day practice of care workers.



P13-003

UTILISING SELF-SERVICE DIGITAL KIOSKS TO ENGAGE PATIENTS IN DEMENTIA RESEARCH

Adam Smith*, Institute of Neurology, University College London, London, United Kingdom and Piers M Kotting, Medical School, University of Exeter, Exeter, United Kingdom

Abstract:

Objective: Join Dementia Research is UK service developed to improve public access to research, and to help researchers recruit to studies. Recruitment to the service is encouraged in appropriate NHS healthcare settings. Delivery is heavily reliant on printed leaflets, posters and staff time to talk patients. This is expensive and unreliable as staff are under pressure and have little time.

To support staff, we developed a self-service digital information / registration kiosk that could improve communications with volunteers. This pilot has been measured over the past six months, as an interim review, and further measurement will continue to end 2018, acting on lessons learnt.

Method: We developed a simple website, which provides basic information on dementia research, and allows the user to provide a small amount of information, enabling follow-up by email or telephone. The website runs on a Wi-Fi dependant tablet computer, fixed into a branded display kiosk. Kiosks were distributed to GP surgeries, NHS Memory Clinics, Pharmacies and Hospitals. The tablets are connected to remote monitoring and management software, and registrations are tracked through from enquiry to registration. The information provided encourages the volunteer to register with Join Dementia Research.

Result: Between October 2017 and January 2018, 110 kiosks were distributed, to 37 GP Surgeries, 11 Pharmacies, 19 Memory Clinics, 2 Hospitals, 11 community clinics, 30 research networks / roaming between clinics and 76 were activated. The kiosks were on for the equivalent of 2240 days (average of 29.4 days per kiosk from a possible 80 days). Overall they received 609 enquiries, 550 opting for email follow-up and 59 telephone. Resulting in the Join Dementia Research website receiving 438 visits and 143 total registrations.

The best performing kiosk was active on 76 days, receiving 0.7 enquiries per day, generating a total of 51 enquires and 23 registrations in Join Dementia Research (45% of enquiries converted to registration).

Conclusion: Feedback from sites and users is positive, the kiosks are popular and seen as an interesting and easy way to engage with potential volunteers. The logistical difficulties have been significant, with 25% of sites having one-off or ongoing connectivity issues or governance challenges. A third of the kiosks have not been connected, with receivers raising workload and time as being the reason for not installing. A number of kiosks have very low engagement levels, and this appears to be due to the positioning in places other than waiting areas. There has also been a significant management cost in monitoring usage, feeding back to sites, and encouraging sites to ensure kiosks were on and active.

Despite the difficulties the outlook remains positive. Had all kiosks performed to the standard of the best performing, the pilot would be extremely successful with over 2000 registrations, which over a year would make the cost per registration under £5. The ongoing challenge is to understand what that site is doing differently and what more can be done to bring the other 109 up to that standard in the remainder of 2018. The kiosks will remain active and will be rotated in 2018, with further reporting and consideration given to follow-ups and site content.

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Engaging people living with dementia and care partners - Poster

P13-004

THE FIRST EXPERIENCE OF A WORKING GROUP OF PEOPLE WITH DEMENTIA FOR FEDERAZIONE ALZHEIMER ITALIA

Mario Possenti Mr* and Francesca Arosio Dr., Federazione Alzheimer Italia, Milano, Italy

Abstract:

Federazione Alzheimer Italia has activated since late 2017 in its Milan office a working and confrontation group of people with dementia, so that they can be, within the organization, voice, testimony and help to debunk those myths that still today dementia brings with it

Starting from the precious first Italian testimony, the one that Father Politi did, and thanks to experiences of international groups such as Dementia Alliance International and the European Working Group for People with Dementia, it was possible for the Italian group to move the first steps on mutual knowledge, set job goals and above all, in a few weeks, to involve a good number of enthusiastic participants.

Currently the working group, composed of 4 people with different diagnoses of dementia (average MMSE 17), meets weekly to discuss various issues and it concludes with a convivial moment and the involvement of family members. The main issues to date addressed in the group concern the path of the disease: in a climate of friendship, each member of the group feels free to share the strategies identified to cope with daily difficulties, the daily experiences at home and in the community, fears about the course of the disease and, above all, suggestions and messages that they would like to take outside the context of the group.

The point of view of the person with dementia, offered directly from within the disease, provides one of the most valuable indications for both caregivers and for initiatives such as the Dementia Friendly Community; in this way the group comes in play and advocates for the protection and the recognition of the rights of each person with dementia.

The group, after a few months from its establishment, has been involved, as the first and expert interlocutor, in a qualitative study about an active methodology for the re-enactment of memories. As a close-knit working group, the members have given their opinion, shared their experience using the instrument so as to be able to evaluate its use in a wider context such as nursing home or less controlled as the home environment.

Federazione Alzheimer Italia believes that the main benefits that can derive from participating in a support group for people with dementia are the following:

1. Offer a safe space for sharing experiences, changes and all about living with dementia.
2. Reducing the isolation that dementia often brings with it.
3. Increase the motivation to face everyday life by providing a purpose such as collaborating with a patient organization.
4. To show the person with dementia is not alone in facing the disease and that this condition allows the development of new relationships.
5. Be the spokesperson of a positive testimony to cope with the stigma associated with dementia
6. Be an invaluable asset for the patient organization and for the Community in order to better understand the needs of people with dementia and to guide the support initiatives.

In conclusion, it is a matter of offering the people with dementia the opportunity to be and to feel useful and real spokesperson of the complexity of the disease and not hide behind the "nothing can be done because there is nothing to be done". The group has already achieved a first important goal: to enhance the quality of life of the participants and, above all, to restore the importance of life experience of these people that, despite the disease they continue to be what they are, a father, a mother, a child.



P13-005

EXPERIENCES OF FAMILIES SUPPORTING ELDERLY DEMENTIA PATIENTS UNDERGOING HEMODIALYSIS

Sachiko Hara*, Shimane University, Izumo, Japan and Ryo Tachihara, Shimane Prefectural Central Hospital, Izumo, Japan

Abstract:

Objective: The purpose of our study was to clarify experiences of families who support life of elderly dementia patients after onset of hemodialysis treatment.

Method: Semi-structured interviews were conducted for 7 family members of elderly dementia patients undergoing outpatient hemodialysis treatment, and the answers were qualitatively and descriptively analyzed.

Result: The results were classified into 5 categories: 1) attentively observe the treating doctor's cautions which the patient forgets, 2) cope with difficulties in undergoing hemodialysis, 3) devise methods to enable the patient to continue personal pleasures as before starting hemodialysis, 4) find and manage physical problems which is difficult for the patient to convey by words, and 5) difficulty in maintaining mental stability of family members while watching the hemodialysis treatment.

Conclusion: Family members were noted to have been helping patients to undergo hemodialysis considering the patient's capability, while coping with words and behavior of the patient, daily life, and physical condition. Appropriate support measures by medical professionals is necessary as early as possible after onset of dialysis treatment, to enable care of the patient by family at home. Also, relationship with the family members is important though acknowledging their effort in respecting and bringing out the remaining capability of the elderly dementia patient.





POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-006

EVALUATION BEFORE AND AFTER CARE INTERVENTION FOR THE ELDERLY WITH DEMENTIA APPLICATION OF 18-ITEM DEOS (DEMENTIA ELDERLY ODAYAKA SCALE) IN JAPAN

Hiromi Tsujimura¹; Makoto Osawa²; Setsuko Makita²; Kiyomi Yamazaki²; Risa Matsumura²; Shinichi Ito³; Takayoshi Sato³; Azumi Yoshizawa³; Kazumasa Suzuki⁴; Shizuko Niina⁴; Eriko Matsumura⁴; Takashi Shimada⁴ and Hajime Kanai⁴, (1)Graduate School of Health Sciences, Gunma University, Maebashi, Gunma, Japan, (2) Oido Clinic, Isesaki, Gunma, Japan, (3)Oido Group home for the elderly with dementia, Isesaki, Gunma, Japan, (4)Oido Daycare Service Facility, Isesaki, Gunma, Japan

Abstract:

Background: The authors developed a scale (DEOS: Dementia Elderly *Odayaka* Scale) to evaluate the psychosocial aspects of elderly people with dementia living in facilities and at home. The DEOS can be used to assess their Well-being, such as personhood, their relationships with their surroundings and expression of emotions. **Objective:** The aim of this study was to apply the 18-item DEOS to elderly people with dementia and to examine its characteristic and usefulness. This gives suggestions on the environment and the elderly care that elderly people with dementia can spend well-being. **Operational definition of odayaka:** In Japanese, the word odayaka generally means mental stability and quietness. In the present paper, odayaka was additionally regarded as meaning an ability to interact with one's surroundings and to live in one's own manner despite a decline in cognitive function as a result of dementia. **Method:** Facility staff conducted care taking into consideration the individuality of the subjects and evaluated using DEOS at the beginning of the intervention, one month, and two months later. Furthermore, we analyzed the changes over time of subjects' behaviors along with the score. This study was approved by Gunma University Ethical Review Board (No. 2016-034). **Result:** Thirteen subjects (2 men, 11 women) with an average age of 80.5± 6.5 years were included in the study. The largest proportion of dementia diagnosis (23%) was Alzheimer's disease (AD). subjects who use daycare service facility were the most frequent (50%). Approximately 60% of the total cases increased the score. For the two men, when we approached communication and leadership according to their individuality, we confirmed a rise in score regarding "social interaction" one month, and two months later. We confirmed an increase in the score of the item of "Being able to express emotions (such as pleasure and suffering)" for 2 cases among five cases of aroma massage. **Discussion:** The staff carried out aroma massage one to one while talking with the subjects, and it is affecting the evaluation that they provide opportunities for expressing emotions. In this survey, there are not many cases where the score has increased due to care intervention, and it is necessary to assess based on their treatment situation, physical condition, and mental condition. **Conclusion:** The DEOS can be used to evaluate the effects of interventions also as a scale to plan care that takes advantage of the patient's positive qualities.

This study was conducted by Grant-in-Aid for Scientific Research(C) (15K11748) of Japan Society for the Promotion of Science.



POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-007

EVALUATING LIQUID GALAXY-BASED REMINISCENCE THERAPY FOR PEOPLE WITH DEMENTIA: TIME TRAVELLING WITH TECHNOLOGY (TTT)

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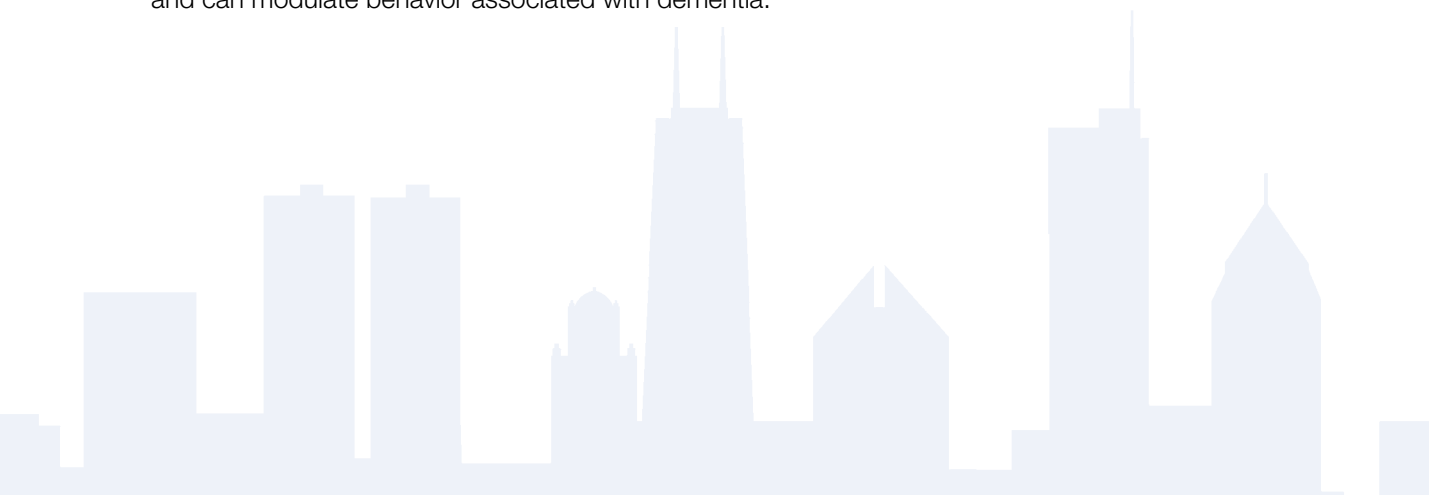
Abstract:

Objective: Reminiscence Therapy (RT) provides an opportunity for people with dementia to talk about memories. Photographs, for example, may elicit recall of life experiences, promoting communication and helping sustain relationships. This presentation investigated whether coupling RT and immersive technology is feasible and beneficial in a residential aged care facility in Sydney, Australia. It was hypothesized that if a sense of envelopment and continuity with personally meaningful “landmarks” enriches RT then an experimental group experiencing a full immersive, dynamic experience will show reduced behavioural problems from pre- to post-intervention compared with a control (no envelopment, continuity) condition.

Method: Five large immersive displays with participants and facilitator “travelling through” pre-loaded Google Earth and Streetview landmarks formed the 6-week group intervention. Amount of immersion (3 displays) and dynamism constituted a control condition with landmarks instead presented as static, large ‘postcard-like’ images. Participants were administered the Mini Mental State Examination (MMSE), the Neuropsychiatric Inventory (NPI) – Nursing Home version and the Quality of Life – AD (QoL-AD) at baseline. The NPI and QoL-AD were re-administered at the conclusion of week six. Video coding for engagement based on whether they were emotional, verbal, visual or physical occurred for five minutes for each resident per session.

Result: Of the 33 residents recruited, 24 fulfilled the minimum three session attendance criteria for inclusion in the final analysis with 11 in the experimental and 13 in the control. The range and mean of MMSE scores from both groups prior to the experiment were similar ($M=13.55$, $SD=5.54$ experimental versus $M=15.23$, $SD=5.93$ control $t(22)=0.72$, $p=0.482$). There was a significant decrease in mean scores on the NPI from pre- to post-intervention in the experimental ($M=31.64$, $SD=19.11$ versus $M=24.27$, $SD=11.98$; $t(10)=2.27$, $p=0.046$) but not in the control condition ($p=.70$). No differences were found for on the QoL-AD for the experimental ($p=.90$) or the control ($p=0.83$).

Conclusion: It appears that RT combined with immersive technology and in a small social setting is feasible and can modulate behavior associated with dementia.





POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-008

CARING EXPERIENCE OF A PATIENT WITH YOUNGER ONSET FRONTOTEMPORAL DEMENTIA (FTD) SHARED BY HIS DAUGHTER WHO IS A PHYSICAL THERAPIST

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Abstract:

Objective: Frontotemporal Dementia (FTD) tends to occur at a younger age and causes deterioration in behavior and personality, language disturbances, or alterations in muscle or motor function. It is often misdiagnosed as a psychiatric problem at its early stage. Living with patients diagnosed as FTD usually is very challenging and stressful because of the personality changes and behavioral problems. The purpose of this report was to share the experience of a daughter, who also is a physical therapist, to deal with a patient with younger onset FTD.

Method: My father is a 71 y/o male who is diagnosed and treated as depression problems from psychiatrists for 15 years. His past histories include coronary artery disease post replacement of 2 stents, COPD with bronchodilators for 10 years, DM with insulin injection for more than 20 years. He began to have some behavior and personality change since the September of 2016. His psychiatrist suspected that he had delusional disorder and gave treatment but in vain. Later he had unsteady gait and incontinence and visited a neurologist who diagnosed him to be a case of FTD by clinical symptoms and brain MRI. I tried to find the effective treatment from evidence-based medicine and found the only effective treatment is exercise and regular structured routines. I also search and received further training to be a physiotherapist of dementia. For 8 month all my siblings tried many ways to care and live with my father including medicine, caring methods, exercise. Throughout this process, we also changed the way to think about dementia.

He was very anxious in the beginning and can't stay in one place for more than 20 minutes. Besides it's also difficult for him to interact with strangers. My younger brother was the major caregiver. Every day he held my father's hand to walk around outside our home for 2 hours. In the afternoon, he usually accompanied him to take the bus, where is the best place to calm him down.

Because of our government's long-term care policy and the integrated dementia care, my father was referrals to the daycare community to join the elderly courses and activities. Before he attends the courses, I try to educate members or caregivers in this community about the right way to exercise and enhance cognition, and the dementia friendly attitude. On the other hand, we also tried to maintain his skills of daily living skill, using verbal praise and encouragement to reduce the movements' assistance.

Result: He became more stable since October 2017, after a series of trainings and trials, and our family can live with him easily and happily. His function in daily activities scored by Barthel Index improved from 47 (2017/01/01) to 70 (2018/01/01) with most significant changes in feeding and dressing. He also got improvement in transfer, stairs climbing and walking ability and better control in the bowel and bladder habit. He can more easily to face the strangers with better communication and memory abilities.

The depression and anxiety of caregivers is also decreased as presented in Self-report Chinese version of Depression Anxiety and Stress Scales (DASS-21) from 41 point to 9 point.

Conclusion: Caring a family member with dementia is a difficult and challenging job. Without proper education and knowledge of this disease will made the whole family in suffer or even torn apart. In the case of my father, we believe that his great improvement was made from good caregiver-education, good country policy, and friendly community.



POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-009

GIVING VOICE TO LIVING WITH ALZHEIMER'S - COMMUNITY CHORUSES OF JOY, MEANING AND CONNECTION**Mary J. Lenard**¹, 4627 Bruce Ave., Giving Voice, Minneapolis, MN**Abstract:****Background:**

In late 2014, two colleagues with different areas of expertise launched a pilot project called Giving Voice Chorus. It was a specially designed community choir for persons with Alzheimer's and other dementias and their care partners. It specifically targeted those persons who remained living in the community after an Alzheimer's (AD) diagnosis, primarily early-mid stage individuals. Some of the initial goals were engagement and empowerment of those living with dementia, creating opportunities for joy and friendship, and ultimately, changing the stigma for those who lived with dementia.

While designing the pilot, research was emerging about music memory and the retention of music in a part of the brain not damaged by Alzheimer's. A 2013 study from the University of Helsinki found that singing familiar songs provided improved mood and cognition, strengthened emotions and working memory and created a positive social interaction for both the person with dementia and care partner. In addition, the *Alive Inside* documentary further fueled interest in engaging people in singing together before placement in nursing institutions. We launched our first chorus with about 28 members in September 2014 at MacPhail Center for Music in Minneapolis. In 2018, there are four Giving Voice choruses in the Minneapolis-St. Paul Area and 19 Giving Voice-inspired choruses that have launched world-wide, including a chorus for African Americans through St. Paul faith communities.

Approach:

The best practice characteristics of a Giving Voice Chorus include a specially trained music director, a wide familiar repertoire, personalized music books and practice CD's, weekly rehearsals and public performances, inclusive/adaptive environment, ample social time and dementia-friendly trained volunteers. It was essential to capture information about the benefits of this multi-sector program since so few engagement programs exist in the community. There are two distinct research projects that encompass the first 3 years of Giving Voice work. First was a participant benefit study conducted by Helen Kivnick, PH. D, LP, LICSW of the University of MN that conducted qualitative interviews with 12 dyads who sang in the chorus for eighteen months. A second study was conducted by Bhavani Kashyap, Ph. D. with HealthPartners Center for Memory and Aging that assessed persons with dementia and care partners on mood, well-being, and quality-of-life indicators in a year-long study.

Findings:

Both studies indicate that singing together has numerous benefits for both the person with AD and the care partner. Many of these benefits improve singer's overall health through an increased sense of purpose, higher quality of life or reduction in depression. One of key findings is a significant decrease in social isolation expressed by all singers. Singers felt empowered to build their own community of music and sharing of their story. Persons with AD and their care partners began to interact differently when their entire identity was not eclipsed by an Alzheimer's diagnosis.

Conclusion: Dementia-friendly community choruses are high impact programs that engage those with dementia and care partners in positive and meaningful ways. Music participation and socialization combine to address social isolation, improve relationships, increase well-being and begin to change stigma across the community.



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P13-010

DEMENTIA CARE COMMUNICATION VIA SOCIAL MEDIA APPROACH

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Abstract:

Introduction

There are more than 270,000 individuals living with dementia in Taiwan. With their caregivers, at least 550,000 people are in urgent needs of information and resources related to dementia. In order to cope with increased prevalence rate of dementia due to aging society, Taiwan announces 2018-2025 TAIWAN DEMENTIA PLAN, where is aiming to build 63 dementia care centers and 368 dementia community service offices by 2020, and to establish correct understanding and support of dementia from 5% to 7% by 2025.

To present information on the most-often-used social media platform and to engage most audiences are the initial objectives, NTPC government, for the first time, decided to work with United Daily News (udn) Health Division, one of the most influential media groups in Taiwan, which not only convey public's voice, but continuously focus on government policy such as Long-term Care Policy 2.0 (LTC), to establish a social media approach. Based on Facebook statistics showed Taiwan has more than 18 million users, a Facebook fan page "Dementia" was formed in 2017.

Objectives: The initiatives of Dementia fan page are clearly defined as "you are never alone" and "everyone affected by dementia has access to specialist care, support and advice whenever and wherever it is needed."

Results: Within only 1 year management, Dementia fan page now owns almost 43K fans and followers, where has become the most active fan page in Taiwan. The fans' figures are mainly middle-age caregivers (45-55y), of whom 77% are women.

From Dementia fan page analysis, the most frequent asked questions are correct dementia-related information and resource (e.g. fingerprint filing, long-term care application) 52.5%, caregivers' consultation (e.g. case discussion) 18.6%, and dementia Q&A (e.g. dementia classification) 17.0%. More than 1,612 inquiries have been solved by Dementia fan page.

Furthermore, couple extension programs were implemented to raise dementia awareness one step further. A dementia caring book "The 100 questions about Dementia" was published based on the true inquiries from fan page.

Unlike most fan pages would post medical-related information, Dementia fan page translates difficult professional knowledge and policy into understandable contents which easily resonates caregivers. Therefore, more and more dementia families are willing to share their stories and ask for assistant. Active discussions help to transform caregivers' mindset and make them no longer confined themselves (for example, sending dementia individual to nursing home for professional care is not a bad thing), and more practical actions are taken by caregivers to improve current situations (e.g. fingerprint filing at police station is one solution to track dementia patients in case if they are lost).

Conclusion: The core objective of dementia fan page is to serve as an informative community for anyone who wants and needs to understand dementia and to provide support. In order to maximize the visibility to society, fan page not only integrates online and offline resources (e.g. consolidating articles, activities from related entities, providing daily practical content etc.), also provides various useful tools such as dementia videos, caregivers' feedbacks and physicians and hospital information. In addition, fan page digests feedback from fans and uptakes professional monitoring reports to develop innovative approach.

Dementia fan page <https://www.facebook.com/NTCDementia/?ref=bookmarks>



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P13-011

ENGAGING PEOPLE LIVING WITH DEMENTIA AND THEIR CARE PARTNERS

Anthea Innes^{*}, Salford Institute for Dementia, University of Salford, Salford, United Kingdom

Abstract:

It is now widely accepted as good practice to engage people living with dementia and their care partners, but doing so can pose challenges. This paper will discuss how the Salford Institute for Dementia has developed a process, over a period of 3 years, to engage people living with dementia and their care partners in a variety of ways to inform the work undertaken by a University. The first example is the Salford Institute for Dementia Panel of Dementia Associates. Dementia Associates at Salford are people living with dementia, their current care partners and also care partners who continue to lobby and advocate for people living with dementia after their relative or friend has died. Such individuals participate in a forum we have established where the Dementia Associates advise on all aspects of the work we undertake. This includes:

1. Research, as members of advisory groups, commenting on bids in progress, discussing ideas for new research, helping to disseminate research findings as well as the more conventional research participant role.
2. Dementia associates co-facilitate 'Dementia Friends' training sessions with the Institute staff as part of the UK Alzheimer Society dementia friends initiative to students, staff at the University and within the local community; deliver lectures to students on a range of University courses, for example nursing students and architecture students; and they have produced video diaries to share their experiences with students.
3. community engagement work. Dementia associates have led community initiatives in shopping precincts, the local library and leisure facilities to raise awareness of dementia in the community. They have co-presented at local, regional and international events to ensure the lived experience is represented to maximum impact to help improve the lives of those living with dementia. They have advised on the physical build of the 'Dementia Hub' and all the activities and groups the University offers to people with dementia living in the community.

The second example is the groups the Institute runs; namely SIDs Café, The Good Life Club and a Music Café. These initiatives have developed through consultation with people living with dementia in the community and provide opportunities for people with dementia to avail of peer support while also participating in research and evaluation studies.

In these ways we are engaging people living with dementia to enhance the engagement of people living with dementia through opportunities for inclusion and involvement.





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Engaging people living with dementia and care partners - Poster

P13-012

EQUINE GUIDED PROJECT: WORKSHOPS FOR PEOPLE LIVING WITH EARLY STAGE DEMENTIA AND THEIR CARE PARTNERS

Nancy A Schier Anzelmo^{*1}; Paula L Hertel¹ and Sarah Tomaszewski Farias², (1)Connected Horse, Rocklin, CA, (2)Neurology, University of California Davis, Davis, CA

Abstract:

Connected Horse: Equine Guided Support Project

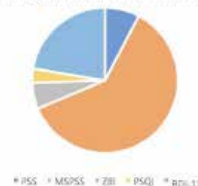
Abstract Pilot 1 Stanford University & Pilot 2 University of CA, Davis

There are 35 million people living with dementia worldwide. This number is expected to triple by 2050. Family caregiving remains the most common form of care, although researchers worldwide find that stress significantly typifies this experience. Persons are diagnosed earlier in the process and living with early-stage dementia, becoming more of a global reality. Yet few specific services exist to meet the needs of this population and their family caregivers.

Person Living with Dementia
Mean Changes in Pre and Post Assessments: N=27



Care Partner
Mean Changes in Pre and Post Assessments: N=27



The Connected Horse project is an innovative approach that offers considerable promise for application beyond Northern California, where it was conducted. The program includes an introduction to an equine facility followed by two 5-hour workshops, focused on therapeutic activities with horses, discussion groups and awareness practices led by trained facilitators. Activities with horses included observing herd behavior, grooming, leading, and connecting over the fence - all intended to elicit sensory responses and teach non-verbal communication skills to both care partners (CPs) and persons living with dementia (PWD). Reflection on these experiences was the discussion goal. The Pre/post-test design used standardized measures of stress, burden, mood, and social support for both CPs and PWD. The two pilots have had a total of 60 participants, between two university sites. A total of 27 dyads were completed at the second pilot site, UC Davis, in collaboration with the Alzheimers Disease Center and School of Veterinary Medicine.

The results were promising for the 60 person sample size. Quantitative indicators showed overall positive trends in measures of support (MSPSS mean delta +2.99), burden (ZBI mean delta +2.), stress (PSS mean delta +.86), and sleep (PSQI mean delta +1.17), with a decrease in undesired behaviors of persons with dementia. Qualitative indices showed positive increases in dyad communication and increased awareness of individual abilities to adapt to changes in roles.

Third and fourth pilot sessions are scheduled at UC Davis in 2018. Two follow up booster sessions for participants are scheduled for 2018. Future studies will include multiple sites and an appropriate control group. Discussions with therapeutic equine centers expands the promising outcomes of the pilot study.



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Quantitative and qualitative findings in both studies indicated significantly increased positive perception of social support, greater sense of reciprocity, awareness, upliftedness and appreciation of one another in dyads. Trends for improved mood in both members of the dyad were noted.

Future plans include partnering with other sites, in the community and expanding program's positive outcomes on a larger scale. In both studies significant positive change scores were found on the social support scale (MSPSS) and depression scores decreased (BDI II). Preliminary analysis of the qualitative data supports trends for improved mood, greater reciprocity, awareness and appreciation of the relationship, in both locations.

The goal is an alternative approach to enhancing quality of life for people living with dementia and their care partners for greater acceptance and appeal to a broader spectrum of individuals. Ultimately, the magic that unfolds between the dyads and horses in a brief span of time can benefit individuals of various backgrounds and needs. We are hopeful this program is disseminated to many.





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P13-013

MEANINGFUL ENGAGEMENT OF PEOPLE WITH DEMENTIA

Mary Schulz, Information, Support Services and Education, Alzheimer Society of Canada, Toronto, ON, Canada and **Laura Garcia**^{*}, Education, Alzheimer Society of Canada, Toronto, Canada

Abstract:

Historically, the Alzheimer Society of Canada (ASC) has focused on providing support and education to caregivers of people with dementia rather than people with dementia themselves. However, there is a growing demand to expand the ways in which people with dementia can and want to contribute to all aspects of the Society's operations, from decision-making to providing input into dementia awareness strategies, programs and services. With this in mind, ASC developed an engagement resource guide which provides a framework for the promotion of well-being, choice, autonomy and open communication, all of which are foundational to the meaningful engagement of persons with dementia.

In 2006 ASC commissioned a study to help identify strategies to promote the active participation of people with early stage dementia in the Society's policy, research and service delivery. ASC followed up with another study in 2011 to obtain specific recommendations on the steps needed for successful engagement of people with dementia in the work of ASC. Acting on these recommendations, in 2012, ASC formed an advisory group comprised of persons with dementia from across Canada. The group's mandate was to advise and share their perspectives on how ASC currently engages people with dementia in their work and what needs to be done to make the engagement of people with dementia more meaningful and fulfilling for both them and ASC.

The advisory group helped develop an "*Ethical Framework on Engaging People with Dementia*" which guided ASC's future work in this area. In addition, with the advisory group's input, a guide on how to meaningfully engage people with dementia was developed. This guide provides tools, resources and strategies to assist organizations in promoting the engagement of people with dementia.

Being engaged meaningfully provides people with dementia with an opportunity to give input into decisions that directly affect them, which can contribute to a sense of personal worth. In addition, it provides a vital perspective on different issues and promotes communication among people with dementia, Alzheimer Society staff and researchers. The resource guide will help build capacity within organizations to collaboratively address the needs of persons with dementia.





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P13-014

WISCONSIN'S DEMENTIA CARE SPECIALIST PROGRAM: FROM PILOT TO PROGRAM AND BEYOND

Katelyn Marschall^{*}, Wisconsin Department of Health Services, Madison, WI and Kristen Felten MSW, Wisconsin Department of Health Services, 1 W Wilson, WI

Abstract:

Aging and Disability Resource Centers (ADRCs) offer the general public a single source for information and assistance on issues affecting older people and people with disabilities, regardless of their income. These resource centers are welcoming and convenient places for people with dementia and their caregivers to get information, advice, and access to a wide variety of services. The Dementia Care Specialist program enhances the capacity of ADRCs to work with individuals and families living with dementia. From 2014-2017, the Department of Health Services funded sixteen Dementia Care Specialist positions, covering 26 counties. Beginning in 2015, Dementia Care Specialist positions were funded in three Wisconsin tribes to serve the Native American population. Additionally, the program will be expanded in 2018 to include an additional five Dementia Care Specialist positions.

Everyone's experience with dementia is unique, and connecting people with dementia to a community-based dementia specialist can ensure that supports and services are tailored to the needs of each individual. Dementia Care Specialists train ADRC and tribal agency staff to perform memory screens for individuals to determine a need for clinical follow-up with a primary physician or other health care professional. They also provide information and assistance to people with dementia and their caregivers and connect them with support and options for home help, long-term care, and other needs.

Dementia Care Specialists have been effective catalysts in promoting dementia-friendly communities. They work with businesses, employers, local organizations, and the community to increase awareness of the unique needs of individuals with dementia and their caregivers. Dementia Care Specialists provide community education; mobilize community resources; and consult with law enforcement, adult protective services, crisis response teams, medical providers, and others who need information regarding dementia-related issues. Dementia Care Specialists facilitate and lead efforts to make local communities safe and welcoming for people with dementia. In 2016, Dementia Care Specialists attended 1,870 community outreach events, reaching nearly 41,000 people.^[1] Outreach events included health fairs, information booths, public speeches, content-expert presentations, radio shows, and discussion panels.

In this session we will discuss the history of the DCS program, the impact that the program has made in Wisconsin, and the future development of the program.

^[1] <https://www.dhs.wisconsin.gov/publications/p01775.pdf>





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P13-015

MOVING BEYOND ACTIVITY PROGRAMMING TO A MORE PURPOSEFUL, ENGAGING LIFE

Virginia Bell^{*}, Christian Care Communities, Lexington, KY and Mr. David Troxel, Best Friends Approach, Sacramento, CA

Abstract:

The presenters surveyed via phone, email and personal meetings 21 persons with younger-onset dementia and asked them what they still wanted to enjoy in life. Results included: time with family and friends; helping others; productive work; creative pursuits; time in nature including time with pets and animals; access to the Internet; and advocacy for themselves and others.

Based upon this survey and the presenter's own work in home-based, day center, and residential care settings this presentation will discuss the importance of creating therapeutic environments for persons with dementia utilizing a more progressive view of activities. We define "therapeutic environments" as environments that are healing. For persons living with dementia this could include music, exercise, conversation and friendship. It's time to move beyond Bingo and trivia to more meaningful opportunities for persons with dementia, particularly since, in many ways, socialization is the treatment for dementia, particularly with the ongoing lack of disease-modifying medications.

Long term care companies in the United States are recognizing this trend, increasingly changing the job titles of activity staff to job titles that reflects the importance of living life vs. programming. New titles include Director of Engagement or Enrichment, and even Director of Fun.

This presentation will offer some key steps to creating a more life affirming activity programming and will also describe how to coach and educate family care partners to embrace some of these ideals with the person living with dementia. Activities with engagement:

- Include purpose and opportunities to build self esteem
- Help persons experience success
- Encourage physical activity which contributes to fall prevention and overall wellbeing
- Encourage friendship and connection
- Involve ongoing and life-long learning
- Fight boredom which can lead to behaviors challenging for care-partners

The presentation will then offer specific suggestions for various care settings. This will include:

- Interacting with the websites of museums from around the world.
- Baking cookies to enjoy and give to local first responders (firefighters, police, ambulance teams) or baking dog biscuits to give to a local animal/rescue shelter
- Creating interesting and artistic collages.
- Trying new and novel things -- expose the person to musical genres that may have previously been unfamiliar (opera, country western or jazz).
- Instead of exclusively following a written calendar of events, train staff on the importance of unstructured time, conversation, relationships and even 30-second moments that foster friendship and connection.

The authors conclude that in life many of us complete tasks and activities to achieve a certain end (paint a room or finish a scrapbook of family pictures). In dementia care, it's the journey not the destination that adds to quality of life.



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P13-016

THE LANGUAGE OF PUBLIC INVOLVEMENT IN RESEARCH. WHAT'S IN A NAME AND WHY DOES IT MATTER?

Jane F Thompson^{*}, Member of the Public, Canberra, Australia and Belinda Goodenough, Dementia Training Australia, Wollongong, Australia

Abstract:

'Patient and public involvement' or 'Public Involvement' (PI) in all phases of the health and medical research process is an increasingly important theme in theory and practice, as well as becoming a prerequisite for ethical review and funding of research. PI means doing research 'with' rather than 'for' or 'on' people with direct experience of or at risk of a health condition. Practically, this means involving them in all phases of the research process from priority setting to translation into practice.

Few would question *why* we should involve the public in research. The moral/ethical/political reasons should be sufficient ('Research for us, with us'). But, there is also emerging evidence testifying to the assumed value/benefits that involving the public can bring, with increasing demand for this evidence. Nonetheless, the PI agenda does attract skepticism and criticism, even being described as "so conceptually and theoretically vague that it can mean anything (and nothing) and serve a variety of purposes".

As a social movement, PI is "relatively immature and underdeveloped", and the practical application of its principles evolving slowly. The United Kingdom (UK) is seen as a world leader with its visionary organisation INVOLVE which supports public involvement in health services, public health and social care research. In the dementia field, Alzheimer's Society UK provides a great example of involvement of the public in its research program through its extensive Research Network of people with dementia and carers. In Australia, such leadership and clarity of vision, is developing, with some organisations espousing the values of public involvement although it is not yet embedded in our culture and practice. Our peak funding body for medical research, the National Health and Medical Research Council, provides guidance in its 2016 *Statement on Consumer and Community Involvement in Health and Medical Research*. Cancer research has a well advanced PI program but dementia research has some way to go.

The evolving PI movement has a growing lexicon to describe participants and practices ('who' and 'what'). There is not, however, a consensus in terminology. Regarding *who*, the list of labels includes: service users, consumers, carers, citizens, community, patients, the public, lay persons and, simply, persons or people. In Australia, 'consumer' (a term no longer used in this context in UK) is still in common usage, with added complexity in the dementia context: is the 'consumer' the person with dementia, or their carer/family, or both? Regarding *what*, the literature abounds with confusing and inconsistent use of terms like *engagement*, *participation* and *involvement*. While these activities may overlap and be complementary, we recommend that a common understanding for key concepts and definitions must be a priority if the PI agenda is to mature. There are useful frameworks - INVOLVE has provided clear definitions which could be universally adopted.

Why clarity of terms? Firstly, public involvement in research is vital – and *who* gets involved depends on ethical clarity in *what* they are signing up for and in which research phase. Secondly, the evidence-based movement demands precision if we are to evaluate the impact of public involvement in research. As with any construct, we must be able to define what we are measuring. Without precision of language, the power of the PI movement to achieve 'research for us, with us' will be diminished. We cannot afford this loss.



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P13-017

THE ACHIEVEMENT OF ESTABLISHING A COMMUNITY CARE AND SERVICE CENTER FOR DEMENTIA IN SHILIN DISTRICT OF TAIPEI

Dr. Yun Chen Ko; Ming Chen Chen; Yen Ting Tan; Wen Ruey Yu; Chin Yu Ho and Chi Li Liao, Taipei City Hospital, Taipei, Taiwan

Abstract:

Objectives: According to the prevalence of dementia in Taiwan and the population in Shilin district of Taipei, we estimated the dementia population was up to 3652/ 45650 (8%) in people aged 65 and older in Shilin district in the end of 2016. Not only the care of the people with dementia, but also the physical and mental health of the caregivers are our concern. Recently, developing community-based care for dementia has become a part of the long-term care program 2.0 policy of the ministry of health and welfare of Taiwan. We planned to establish a community care and service center for dementia.

Methods: Our target group was people aged 50 and older with clinical dementia rating scale 0.5-2. We chose one space located in the Shilin outpatient department as the community care and service center for dementia, which opened 4 hours per day from Monday to Friday. We combined 1. Medical dementia-care team, included 2 general physicians, 2 neurologists, 2 social workers, a pharmacist, a case manager, a nurse, a physiotherapist, a occupational therapist, a speech therapist, and so on. 2. Volunteers 3. The staff in Shilin health center. We provided supportive services and training courses. For example, we planned combination of cognitive and physical training, animal-assisted therapy, aromatherapy, reminiscence therapy, music therapy and so on to enhance cognitive stimulation of visual, auditory and language for people with dementia. Moreover, we composed support groups for caregivers of people with dementia. Via the leads of counseling psychologists, the caregivers could learn and share the pressure and experience with each other. In addition, the volunteers could do home visits, guided the people with dementia to participate in social activities. We also offered referral service timely. Besides, we tried to form partnership with the community.

Results: From Jul. 31 to Dec.21 2017, we offered 6 services: 1. 21 Health promotion and delaying dementia courses for 15 people with dementia, 53 person-times. 2. 20 interdependent home courses for 26 caregivers and people with dementia, 163 person-times. 3. Home visits for 18 people with dementia. 4. 6 Caregivers courses for 21 people, 66 person-times. 5. 7 support groups for caregivers for 16 people, 31 person-times. 6. Dementia friendly community. We trained 30 dementia friendly volunteers, and 23 stores signed memorandums of understanding.

Conclusions: Via the integration of medical professionals, community resources, social welfare and the health system, we would keep lower the burden of caregivers and improve the quality of life of people with dementia.



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P13-018

CONNECTING TO THE WORLD OF PEOPLE WITH DEMENTIA THROUGH FAMILIAR MUSIC: USING FAMILIAR MUSIC TO SUPPORT PEOPLE WITH DEMENTIA ACROSS MILD, MODERATE, AND SEVERE STAGES IN COMMUNICATION AND INTERACTION

I-Hsuan Tung¹, Taiwan Catholic Foundation of Alzheimer's Disease and Related Dementia, Taipei City, Taiwan

Abstract:

It is human nature to desire connections with others, even if one has a diagnosis of dementia. Nevertheless, communication and connection between people with dementia (PWD) and their caregivers may become more and more challenging as the disease progresses. PWD might have difficulties connecting or interacting with others due to the gradual loss of various cognitive functions, including complex attention, receptive and expressive language, memory, and the ability to understand or interpret physical environment and social context. Sometimes, the loss of functioning could hinder caregivers' ability to connect and communicate with PWD and thus, exacerbate caregiver burden or stress.

Music serves as a means of communication when verbal communication fails. It allows people to express their feelings, emotions, thoughts, and memories and to have dialogues without saying words. Music is an innate ability, as everyone has a "musical child" that responds to music stimuli naturally regardless of any music training. Furthermore, PWD preserve music memory and abilities to engage in music activities. Despite the decline in cognitive functions, PWD can still actively engage in music-making processes, such as rhythmic playing, singing, and vocalizing.

Stage of Dementia ¹	Choices of Music ²	Music Activities (Suggested length) ³	Relevant Behavioral Signs or Responses ⁴
Mild ¹	Self-chosen music ² Familiar music ²	(45-60 mins) ³ Discussion about music-related facts or memories ³ Singing songs ³ Percussion instruments playing with live/recorded music ³ Movement to music: simplified dance movement ³ Supported improvisation ³	<ul style="list-style-type: none"> • → Having eye contact with caregivers⁴ • → Changes in facial expressions or mood⁴ • → Opened body posture⁴ • → Singing or humming along⁴ • → Discussing about relevant facts of the music (i.e. background of the song, the composer, additional information)⁴ • → Verbalizing autobiographical memories or memories related to special personal events⁴ • → Synchronized rhythm playing with instruments⁴ • → Able to mimic dance movement or demonstrate own synchronized movement with music⁴ • → Able to sing or play instruments freely with caregivers' guide and support (e.g. instrument playing, singing along, clapping hands...etc.)⁴
Moderate ¹	Self-chosen music ² Familiar music ²	(30-45 mins) ³ Singing songs ³ Simple percussion instruments playing with live/recorded music ³ Movement to music: simplified dance movement ³ Music-based sensory activities ³	<ul style="list-style-type: none"> • → Having eye contact with caregivers⁴ • → Changes in facial expressions or mood⁴ • → Opened body posture⁴ • → Singing or humming along⁴ • → Verbalizing autobiographical memories or memories related to special personal events⁴ • → Synchronized rhythm playing with instruments⁴ • → Increasing mutual or synchronized body movements⁴
Severe ¹	Familiar music ²	(15-30 mins) ³ Familiar music listening ³ Drum playing ³ Music-based sensory activities ³ Movement to music: assisted or guided body-movement to music ³	<ul style="list-style-type: none"> • → Singing or humming along⁴ • → Vocalizing⁴ • → Rotating the head to localize sound⁴ • → Opening eyes and fixing their gaze on caregivers⁴ • → Changing their tense facial expressions to neutral expressions or displaying delightful expression⁴ • → Increasing limb movements, loosening up body⁴ • → Decreasing resistance to body contact by others⁴ • → Demonstrating mutual body movement (e.g. grabbing caregivers' hands)⁴



POSTER ABSTRACTS

It is important for PWD to maintain autobiographical memories or memories associated with the “self,” otherwise, they may forget who they are. PWD might not be able to recognize their caregivers or understand the context at the moment if they are disoriented to themselves. Therefore, in that situation, caregivers would face great challenges while interacting with PWD. In other words, PWD might be disconnected to their caregivers when PWD show disorientation to the “self.” Evidence has shown that music, especially familiar or meaningful music to PWD, can cue the retrieval of a set of autobiographical memories and meaningful memories related to specific personal events. In a way, music that is meaningful or familiar to PWD can elicit PWD’s autobiographical and meaningful memories, leading to re-establish their gradually fading identity. Hence, they may be able to respond, or “connect,” to their caregivers again through music. Additionally, caregivers can interact with PWD during music-playing processes as sometimes communication happens without words. Music creates a unique context for communication and connection between whoever engaged in the musical processes.

All in all, music is such a powerful yet accessible tool that could help PWD and their caregivers connect with each other. Nonetheless, it may seem challenging to incorporate music for those who have never interacted with PWD in a musical context. As a result, this presentation aims to provide guidelines and rationale for using familiar music to support the communication and interaction between PWD and their caregivers. The presentation includes a table of recommendations for music activities to facilitate interactions between PWD and their caregivers, including choices of music for mild, moderate, and severe cases of dementia. The table would also include meaningful signs that indicate PWD’s attempts to communicate or interact within a musical context, to which caregivers can support and respond further.

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POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-019

ONLINE COUNSELLING AS A METHOD FOR PEOPLE SUPPORTING SOMEONE WITH DEMENTIA

Astrid Linke* and Mrs. Liane Schirra-Weirich, Center for Participation Research, Catholic University of Applied Sciences, Cologne, Germany

Abstract:

Objective: There is an increasing number of people living with dementia and thus family caregivers to report. Their individual situation and possibilities of care become present. Because of a lack of counseling offers or self-help groups in small towns and rural areas, mutual support based on equal demands is needed. Online counseling allows carers to use self-help networks locally independent at home. This also facilitates the use of self-help structures for people who live in rural areas, where access to face-to-face offers requires a big effort. Online platforms enable caregiver participation because of time- and location independence.

The anonymity of using such offers reduces access barriers, especially for carers who otherwise might be afraid of stigmatization or discrimination. According to current studies, caregivers' physical and mental well-being can be guaranteed by using chat groups and online video conferences, guided by trained counselors. They felt less stressed and reported fewer physical complaints. It can be an important approach to new online and social innovations. For this purpose, the project "Online Self-Help Initiative for Family Caregivers" aims to involve caregivers as participants to express their subjective relevance to create tailor-made offers.

Method: Six working packages (WP) are planned within the project duration (2017-2020). WP1 includes two focus groups (n= 12) with caregivers and an online questionnaire for caregivers (n=500); Topics: subjective relevance of caregiving, barriers, wishes and multiplication roles, online support and virtual helping structures and its sustainability. The interest will be the identification and discussion of concepts, suggestions for optimization or ideas for (further) development from caregivers as a participative approach. As a focus of the project, a participatory research approach is used.

Result: Concerning current studies, caregivers describe a lack of a platform that includes several features such as a concurrent advisory item. The focus of further work is the expansion of virtual self-help. It provides family carers and self-help groups with the opportunity to exchange, inform and support each other via various technological communication media (computer, tablet, smartphone) and Internet-based forms of communication. It requires anonymous options to seek advice online.

Conclusion: Caregivers need to be supported in their interests, wishes and barriers of digital media usage. Providers have to create new online service structures to close this supply gap. Digital structures and platforms have to be helpful and available at any time. However, what is helpful in the digital age for caregivers and how can this be implemented by politicians, health insurances and care funds in Germany? This WP aims to give answers to these questions.





POSTER ABSTRACTS

Engaging people living with dementia and care partners - Poster

P13-020

CHANGING INDIVIDUAL AND FAMILIAL GOALS OVER THE COURSE OF ALZHEIMER'S DISEASE

Ms. Elizabeth A. Spencer*, College of Communication and Information, University of Kentucky, Lexington, KY

Abstract:

Every three seconds, someone in the world will develop dementia (ADI, 2018). This pervasive disease impacts not only a vast number of persons, but also their families. As families navigate the caregiving process, various relational goals become salient. Individual task, identity, family relational, and instrumental familial goals are complex, interwoven, and often competing (Caughlin, 2010). This research proposal design proposes a qualitative approach to investigating how family and individual goals change over time, and how these changes impact family relationships. Multiple goals theory of relationships (Caughlin, 2010) will serve as the theoretical framework. Instrumental, relational, and identity goals will be examined for persons and families at the early stage of Alzheimer's or dementia diagnosis, as well as families experiencing the middle and late stages of the disease. Both individual perspectives and family group discourse will be proposed in in-depth family group and individual interviews. Potential practical, theoretical, and methodological implications are discussed. Findings could help inform future research designs, such as development of an online questionnaire in hopes to solicit perspectives from a sample of global Alzheimer's family caregivers at each stage of the disease.





POSTER ABSTRACTS

Models of care - Poster

P14-001

THE LEGACY OF NARRATIVE PARADIGM TO CARE FOR PERSONS LIVING WITH DEMENTIA AND THEIR FAMILIES

Ms. Elizabeth A. Spencer*, College of Communication and Information, University of Kentucky, Lexington, KY

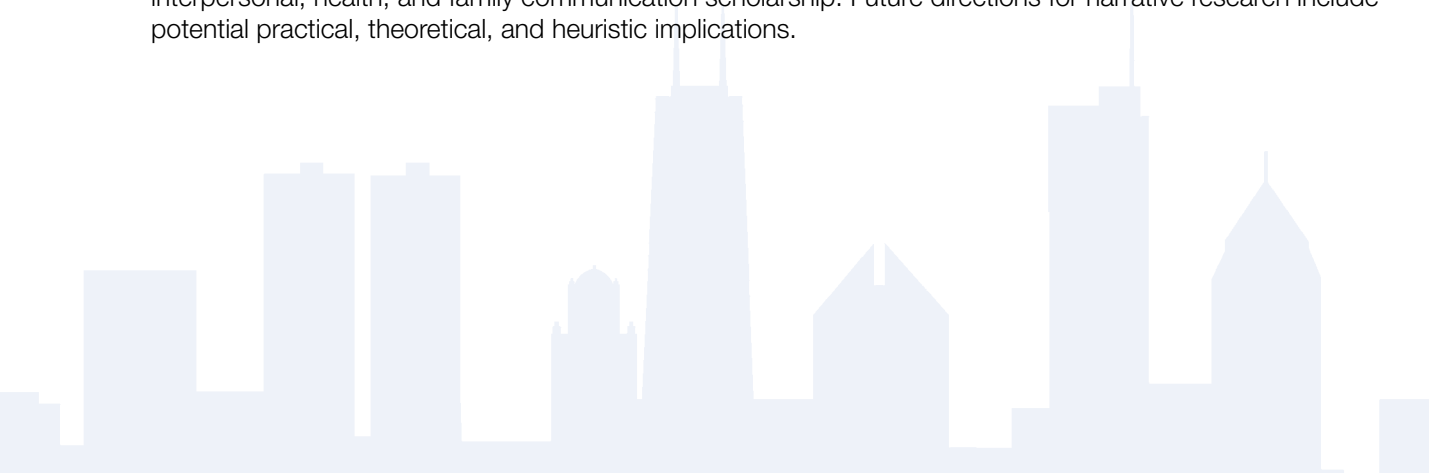
Abstract:

Narrative paradigm (Fisher, 1984) posits that narrative is at the core of humanity. We share our lived experiences through stories and identify with the experiences of others to shape and create relationship and contextualize reality. This critical, rhetorical paper examines progress and potential of narrative at the intersection of health and family communication. Expanding beyond the fidelity and probability tenets of Fisher's paradigm, a new model could first envisage supplemental narrative concepts.

Personal, professional, and academic interest in the concept of narrative drew me to narrative paradigm. Like others, storytelling was introduced to me through my family. Similarly, my family's narrative includes a dementia diagnosis. Reflecting on personal experience of caring for a person with dementia, I consider the journey of other families facing this unique health diagnosis, and the untapped possibilities for interweaving narrative as a means of coping, thriving, and creating lasting legacies. Communication researchers and healthcare professionals can be instrumental forces in testing ways to embrace narrative as evidence in treating patients, a method for healthcare delivery, and a way of understanding the sociocultural nature of human interaction and medical practice.

Narrative performance, narrative inheritance, and narrative legacy are compelling concepts utilized by scholars. Metanarratives have been used by communication and medical researchers to explore opportunities for improving intervention and treatment (Kalitzkus & Matthiessen, 2009). Families facing distinct health challenges such as dementia diagnoses embark upon unique communication quandaries, in particular in health communication settings. We understand others and ourselves through narrative. We make sense of experiences, form and claim identity, begin our own narratives, and participate in culture through storytelling (Langellier & Peterson, 2004). Meaning is constructed and co-constructed through narration. Memorable stories are those that resonate with individual, societal, and cultural ideologies and values. These stories create reality as it is perceived on a personal, family, cultural, and societal level.

Envisioning narrative as a powerful force at the core of human experience, individuals, families, and health organizations can co-create a sociocultural reality of an improved health community. We share our lived experiences through stories and identify with the experiences of others to shape and create relationship and contextualize reality. In this paper, I examine the lineage of narrative paradigm and evaluate its recent evolution. I will commence this exploration of narrative legacy by tracing the ways that narrative has developed in recent years in family communication scholarship and the ways that narrative is used across the contexts of interpersonal, health, and family communication scholarship. Future directions for narrative research include potential practical, theoretical, and heuristic implications.



POSTER ABSTRACTS

Models of care - Poster

P14-002

THE ROLE OF MEDICAL SOCIAL WORKERS IN MULTIDISCIPLINARY DEMENTIA CARE MODEL IN TAIWAN

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Abstract:

Objective: The number of dementia patients in Taiwan is increasing rapidly as the population is aging. Due to the complexity of dementia care, it's important to develop a multidisciplinary care team for dementia for providing better health care and consultation referral services.

Role conflict and ambiguity sometimes occurs among the team members because of the expertise overlap. To clarify the role of medical social workers in such care model, this study aims to explore the gap between the external expectation and the essence of medical social work profession.

Method: This study used purposive sampling to recruit five specialists from a multidisciplinary dementia care team in Chang Gung Dementia Center of a medical center in northern Taiwan. This target group includes a physician, a case manager (nursing background), an occupation therapist, a clinical psychologist, and a certified nursing aide. Five One-on-One interview sessions were conducted to gather their opinions. Table 1 shows the research process, there are three steps including subject preparation, interview and analysis. The interview outline is listed in Table 2.

Result: The results from interviews indicated that all of specialists often work with medical social worker during multidisciplinary dementia care. Their missions include patient non-clinical support, family support, social welfare consultation, advocacy and education activities as well as administrative affairs. Therefore, a medical social worker plays multiple roles as a contact, organizer, coordinator, consultant and referral in the dementia care Team (Table 3).

The specialty and trait which the multidisciplinary dementia care team expected from medical social workers are: ability to handle activities, social resource consulting, connection and integration with government departments, inventory of in-hospital resources, knowledge and skills for dementia care, knowledge of medical treatment process, and provision of counseling for confused family and crisis management. (shown in figure 1). The study result also reveals that the expertise overlap does occur between case managers and medical social workers. For example, patient or patient's family often directly consult case managers about social welfare affairs while disease education in clinic. In addition, the overlap also happens between occupation therapists and social workers during dementia alliance activity or family support activity. Medical social worker plays an essential role in a multidisciplinary dementia care team and has strong connection with team members. However, too much activity planning and administrative works consume their time and energy.

Table 1: Research process

Subject preparation	Interview	Analysis
Identifying study subjects	One-on-one interviews	Opinion extraction
Identifying study method	Word-by-word transcription	Concept forming
Designing interview outline	Additional interviews	

Table 2: Interview outline

How often do you work with medical social worker in daily dementia care practice?
In current teamwork, what task do you think that medical social worker has already taken over?
What else can medical social worker assist in multidisciplinary dementia care teamwork?
What specialty and trait are required for a medical social worker in multidisciplinary dementia care teamwork?

Table 3: Feedback on medical social worker's professional ability from members in multidisciplinary dementia care team.

External expectation of medical social work's profession ability and character	
Physician	Specialty: planning activities for patient's family, providing social welfare consultation, forming support groups Trait: compassion, sociability, good coordination skills
Case manager	Specialty: resource management, being familiar with social welfare Trait: patience, good communication
Certified nursing aide	Specialty: knowledge and skills for dementia care process Trait: diligence, enthusiasm, confidence
Occupation therapist	Specialty: emotionally supporting patient and family, resource integration Trait: warmth, sincerity, trustworthiness
Clinical psychologist	Specialty: planning activities, crisis management Trait: thoughtfulness, willing to help others, strong communication skills

Figure 1: The expectations of medical social worker's professional ability





POSTER ABSTRACTS

Conclusion: This study reveals the opinions of the role of medical social workers in a multidisciplinary dementia care model. Medical social workers have strong connection with team members, however the role conflict and ambiguity hinder them to provide services. This study makes the following suggestions for medical social workers in the model:

- To adhere to strengths perspective and enhance professional knowledge of dementia disease and social work especially family therapy and counseling.
- To facilitate the communication skill.
- To keep following and promote the development of social welfare and dementia policy trend.
- To organization family support groups and lead non-drug treatment groups.
- To enhance social workers' medical knowledge of dementia continuously.





POSTER ABSTRACTS

Models of care - Poster

P14-003

STAFFING STRUCTURES IN HOME-LIKE MODELS OF CARE AND ASSOCIATIONS WITH QUALITY OF LIFE AND HOSPITALISATIONS

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Abstract:

Objective: 1) To describe differences in staffing structures of care staff in home-like clustered models of residential aged care compared to more standard models of care for people living with cognitive impairment and dementia in Australia. 2) To examine associations between staffing structures in residential aged care and quality of life and hospitalisations of the residents.

Method: 541 participants from 17 different residential facilities in four states in Australia were included in the Investigating Services Provided in the Residential Environment for Dementia (INSPIRED) study. The INSPIRED study is a cross-sectional study and included facilities which had a home-like clustered model of care and facilities which had a standard model of care. Quality of life was measured using dementia quality of life measures (the DEMQOL n=231 and Proxy DEMQOL n=539) and a generic measure of health-related quality of life (the EQ-5D-5L, n=535).

Result: Overall, direct care (nursing and personal care attendants) hours per resident day (HPRDs) was significantly higher in home-like clustered models of care compared to standard models of care (0.08 higher (5 minutes), $p=0.006$). Home-like models of care had a significantly higher staffing ratio for personal care attendants to nursing staff compared to standard models of care (mean (SD) 91.6 (3.6) vs. 66.3 (8.4) $p<0.001$). A higher ratio of personal care attendants was not significantly associated with quality of life or overall hospital admissions. However, a higher ratio of personal care attendants was significantly associated with fewer emergency visits including those leading to an admission (IRR 0.60 95%CI 0.43 to 0.84, $p=0.003$) and emergency visits excluding those leading to an admission (IRR 0.40 95%CI 0.25 to 0.67, $p<0.001$), after adjustment for confounding factors including model of care, age, gender, marital status, cognitive function, number of co-morbidities, activities of daily living, social interaction, dementia diagnosis and Neuropsychiatric Inventory.

Conclusion: Overall direct care staff time is marginally, but significantly higher in home-like clustered models of care in Australia compared to standard models of care. Home-like clustered models use a significantly higher ratio of personal care attendants which is associated with favourable outcomes such as fewer emergency visits to hospital. A higher ratio of personal care attendants rather than nursing staff may encourage independence for residents and be a key factor for the health benefits that have been shown for these models of care.



POSTER ABSTRACTS

Models of care - Poster

P14-004

HOME/COMMUNITY-BASED PSYCHOLOGY SERVICES FOR PERSONS LIVING WITH ALZHEIMER'S DISEASE

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Abstract:

Objectives: In terms of differential diagnosis and cognitive rehabilitation, psychologists have provided a variety of services for persons living with Alzheimer's disease (AD). Unfortunately, a comprehensive psychology service directly connecting medical institutes and home/community environment has still been limited. A holistic service model of psychologists has thus been established to simultaneously and continuously empower the whole families.

Methods: This model mainly focuses on 3-level neuropsychological and psychological issues of AD. Firstly, the home/community-based programs for enhancing the literacy of dementia have been organized. Secondly, collaborating with neurologists, the neuropsychological assessments for differential diagnosis of dementias in the community have been utilized. Finally, the grouped counselling programs for sharing emotional disturbances and empowering the capabilities of families have also been developed. Most importantly, these services are well coordinated and collaborated by clinical and counselling psychologists, who continuously work with the whole families from hospitals to their houses.

Results and Conclusions: Through this home/community-based service model, the clinical diagnosis can be more efficient, the knowledge of dementia can be enriched, and the life satisfaction of families can be further enhanced. It thus merits that a multi-domain psychology service without any gaps to comprehensively resolve the psychological disturbances of persons living with AD and their families.





POSTER ABSTRACTS

Models of care - Poster

P14-005

PATIENT- CENTRED INTEGRATED DEMENTIA CARE MODEL

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Abstract:

Objective: The Incidence of persons living with dementia in Taiwan is about 8% over the elders. They have not only the memory problems, but also psychological problems. These always cause huge burdens to their family. Our hospital set up a patient centered dementia care model to improve the quality of care.

- 1. Method:** We set up an integrated team including doctors, nurses, case managers, psychologists, social workers, pharmacists and dieticians.
2. Our hospital set up a geriatric clinic for one stop service for the elders. Those who were confused with dementia problems can register and have family conference at the same place. We have Neurologist, psychologist, Geriatric doctor and herb doctor see the person with dementia problems at the same time. We hold an integrated family meeting at the clinic and discuss the treatment and care plan for them.
3. Our team explained the category and treatment of dementia. Our case manager also educated their care ability and monitor their care burden, we used share decision making method. We share different care choices to, patient's family can choose which is perfect for them, by "SDM" model.

Result: From 2007 to 2016, our clinic had 16,095 visits and we use share decision model. Their satisfaction is 95%. Their care ability improvement rate is 86%.

Conclusion: How to accompany with a dementia relative is very difficult. Our hospital remodeled a software and hardware for people living with dementia. Share decision making is very important which can decrease the care burden to family and respect their dignity for dementia care. Patient centered dementia care model





POSTER ABSTRACTS

Models of care - Poster

P14-006

NUTRITION CARE FOR PEOPLE WITH DEMENTIA IN HOSPITAL

Yu-Fen Lan*, Department of Dietetics and Nutrition, Taipei City Hospital Heping Fuyou Branch, Taipei, Taiwan; Hui-Ping Chang, Department of Dietetics and Nutrition, Taipei City Hospital, Taipei, Taiwan and Dr. Chien-Liang Liu, Taipei City Hospital Heping Dementia Center, Taipei, Taiwan

Abstract:

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Introduction

Dementia is a progressive condition, there is **irreversible long** term cognitive decline. **Dementia** symptoms **vary** depending on the cause, but common problems of eating and drinking include: lack of appetite, struggle to recognise food and drink, forget to eat and drink, difficulties with chewing and swallowing, etc.

Patient-centered care has been widely embraced by many health care organizations in Taiwan. Taipei City Hospital Heping Fuyou Branch was the dementia care center in Taipei City. We constructed the nutrition care model depended on patient-centered approach and the steps of NCP(Nutrition Care Process). Through nutrition intervention to improve patient nutrition status, increase caregivers' intelligence and enhance the quality of life.

People with **dementia**, admitted to **hospital** for **acute medical illness**, and assessed for BPSD and malnutrition risk at admission. For nutrition care, we systematically assessed and identified patients' nutrition problems, then instigated nutrition support and education to resolved problems. We participated the discharge preparation team meeting and developed individualized post-hospitalization nutrition care plan to ensure patient and caregiver understand the importance of follow-up nutrition assessment and education. Dieticians also provided specific information for nutrition follow-up appointments to patient and caregiver.

Execution time and Results

Since May 2017 to January 2018, 53 dementia patients at nutrition risk were referred to dietitians and commenced a nutrition intervention protocol. About 51% patients were able to attend interactive nutrition games and activities, 47% caregivers participated in activities and learned strategies to better communicate with patients. Over 80% **caregivers are satisfied** with the games and activities provided by dietitians.

Nutrition Care Model Purpose

1. Nutrition assessment and intervention to resolve eating problems.
2. Offer nutrition care information and related resources.
3. Develop a **nutrition education video and handouts to improve** caregivers' care knowledge and techniques.
4. Use **multidisciplinary team care** approach to improve nutrition status and **quality of life** by the prevention and **treatment** of complications of **swallowing problems**.
5. Provide comprehensive education program to strengthen caregivers' ability and reduce burden.

Professional team

Neurologist, Specialist nurse, Case manager, Dietician, Speech therapist, Occupational therapist, Physical therapist, Social worker, Dentist



POSTER ABSTRACTS

Models of care - Poster

P14-007

NEXUS – IMPACT ON COGNITION AND ADL IN LONG TERM MEMORY CARE OF AN EVIDENCE-BASED MODEL FOR MEMORY CARE

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Abstract:

Objective: Moving into a nursing home is generally significantly associated with lower score in Mini-Mental-State Examination (MMSE) between last test before and after moving into a nursing home (Gonzales-Colaco et al, 2014).

In general, dementia has been found to negatively affect the person's ability to both function adequately in everyday life and to perform personal activities of daily living. The worsening of ADL performance has been associated with more severe dementia, higher physical comorbidity, agitation and apathy (Helvik et al, 2014).

Nexus is an evidence based program based on 6 pillars of brain health including physical activity (1), social programs with purpose (2), stress reduction (3), cognitive compensation activities (4), a resident support group (5), and a digital brain fitness platform (Brain HQ) (6)

The objective was to measure the impact of the NEXUS program on the level of cognition and ADL performance among residents with mild to moderate dementia in 5 memory care communities in US, CA.

Method: All residents who scored 15 or above on the initial MMSE were included in the NEXUS program. Data on cognition (MMSE) and ADL performance (ADCS) were drawn every 6 months with residents from five communities between 9/1/2015-9/1/2017. Statistical significance was assessed using paired t-test.

Result: At baseline 423 residents were enrolled in the NEXUS program of those 91 completed the MMSE and ADCS at assessment 2 (after 6 months in the program). At assessment 3, 68 residents completed both tests and at assessment 4, 18 residents completed both tests. Results show that those who have the highest scores at baseline in MMSE increase their score significantly from 2nd to 3rd assessment. Moreover, the ones with the highest MMSE scores at baseline are those who complete all 4 assessments as well as increase their MMSE and ADCS scores during the period. The same tendency is seen among those who complete 3 assessments. Among those who participate in only 2 assessments there is a decrease in MMSE score between baseline and 2nd assessment.

Conclusion: Residents with the lowest MMSE score at baseline drop out (either due to cognitive decline, death or moving out) before the 2nd assessment. Residents with the highest MMSE score at baseline survive throughout the period and even increase both their cognitive functioning and ADL performance over the 2 year period. Results indicate that the NEXUS program despite dementia can improve cognition and ADL performance among residents with MMSE score 20 and above at baseline.

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POSTER ABSTRACTS

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POSTER ABSTRACTS

Models of care - Poster

P14-008

HOW DO PEOPLE WITH DEMENTIA AND CARERS DECIDE WHEN TO MOVE TO A CARE HOME?

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Abstract:

Background: Many people with dementia and carers living in their own homes may choose to do so for as long as possible. However, some may choose to move to a care home; and when they decide to move, and the reasons for these decisions remain largely unknown. Little is known about the professionals who may support them to make these decisions as well.

Objectives: Factors leading to the decision to move, the decision-making process, and the timing of the move are complex, and much remains unclear. The study aims to identify factors and drivers when deciding if and when a person with dementia should move to a care home; and to identify what is (if any) an 'optimal' or best time to make this move.

Methods: By adopting a phenomenological stance, qualitative in-depth interviews were undertaken with four groups: social workers, people with dementia, family carers, and care home managers.

Results: All interviews were analysed using the principles of thematic analysis, where themes or consistencies were identified and annotated. Emerging findings indicate the importance placed on risk and safety by all participants and ability of person with dementia to live independently were largely measured against this yardstick. The wishes of the person with dementia were taken into account, in order to minimise distress. Care home managers preferred a move earlier on in the dementia trajectory. However, all groups acknowledged the need to weight up care needs, carer's ability to cope, housing preferences, and mental capacity. The moving-in process is predominately left to family carers, care home managers and their staff.

Conclusions: In the current context of policy rhetoric that tends to encourage people to remain in their own home for as long as possible, along with social care funding cuts, deciding when a person with dementia should move to a care home is doubly difficult. Our study findings will be used to develop specific factsheets to inform and help people with dementia, family carers and professionals with this decision.





POSTER ABSTRACTS

Models of care - Poster

P14-009

PROCUIDA-DEMENCIA STAFF TRAINING PROGRAMME IN MEXICAN CARE HOMES: PSYCHOSOCIAL INTERVENTIONS, PERSON-CENTRED CARE AND OPTIMISE PRESCRIPTION OF ANTIPSYCHOTIC MEDICATION

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Abstract:

Introduction: Mexico is developing a National Dementia Strategy Plan (1). One of its aims is to improve the quality of life of people affected by dementia in long-term care. UK-based studies have identified staff training as psychosocial interventions to decrease depression and behavioural problems in patients in residential and nursing homes (2, 3).

Objective: This study aims to develop a staff training package called PROCUIDA-Demencia and to explore a set of interventions to promote psychosocial activities and optimise prescription of antipsychotic medication. In addition we aim to better results in staff measures to improve their well-being.

Methods: PROCUIDA-Demencia Project was a two stage, mixed methods randomised controlled feasibility and pilot study in seven (500-bed) care homes in urban Mexico. Stage 1 gathered quantitative data at pre, post and follow-up on 55 residents and 96 staff outcome measures. Intervention PROCUIDA-Dementia Vs. Treatment as Usual. Stage 2 collected qualitative data with a total of 60 participants through 12 focus groups with dementia, staff working in care homes (health professionals and professional carers) and family members.

Results: The analyses of quantitative data throughout the temporal series, from baseline to follow-up, showed significant differences both in the life quality of residents ($F=3.22$, $p=0.0271$) and the NPI-NH scale ($F=1.85$, $p=0.0058$) for the PROCUIDA group. A marginal effect of QOL-AD ($F=5.6$, $p=0.0887$) was also evidenced for this group while the remaining outcome measures were not significant (All $p>0.1$) in either the PROCUIDA and TAU groups assessed.

Qualitative Data were analysed applying Framework Analysis. Three themes emerged from residents, four themes from staff and three from family members to understand the acceptance and adherence to the interventions a PROCUIDA-Demencia model of care.

Conclusion: Quantitative and Qualitative preliminary results show that this intervention is feasible. PROCUIDA-Demencia Staff Training Model could be introduced as an easy-to-use set of therapies that benefit cognition, behaviour, mood and quality of life in individuals with dementia, and hence a positive impact on staff working in care homes across Mexico.

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POSTER ABSTRACTS

Models of care - Poster

P14-010

CHANGING DEMENTIA CARE OUTCOMES: ADULT DAY SERVICES AS AN ENGINE FOR REDUCING HOSPITAL READMISSION

Mr. Michael J Splaine*, Splaine Consulting, Columbia, MD and Jeffrey Klein FACH, Nevada Senior Services, Las Vegas, NV

Abstract:

Description: Persons with Alzheimer's disease and related disorders (ADRD) have other health issues--an estimated 75% have at least one additional chronic condition. Persons with ADRD in their medical record comprise 40% of under 30-day readmissions back to hospital. This symposium will highlight Nevada Senior Services' hospital readmission reduction program adopting with fidelity the evidence-based Bridge model of transitions in care.

Objectives

1. By the end of this presentation, participants will be able to describe the impact of hospitalization on persons living with dementia at the individual and macro level.
2. Participants will be able to list the steps necessary in adoption of an evidence based intervention (up to RCT level) with integrity by a community care provider
3. Participants will be able to name and describe the history and components of a local adult day care led services coalition and network assembled to reduce rapid (under 30 day) readmission to hospital of persons with dementia in their care and in the broader community.
4. Participants will be able to describe at least three methods of improving hospital experience for persons living with dementia and their family and community caregivers.

Outcomes: Process outcomes are the evaluation and adoption of an evidence based readmission reduction program with fidelity by a community care provider. Educational outcomes include staff and constituent knowledge on risks of hospitalization for persons with dementia and post hospital delirium care. System outcomes--this project is presented as a work in progress but a serious services coalition has been constructed with formal inter-agency agreements, defined roles, and patient information exchange protocols established between community care providers, families and hospitals A research base has been set by the evaluation contractor that can begin to develop patient and system impact data.



POSTER ABSTRACTS

Models of care - Poster

P14-011

AN INTEGRATED, COMPREHENSIVE CENTRE FOR DEMENTIA IN TAIWAN: EFFICIENCY AND EFFICACY

Dr. Wen-Chuin Hsu¹; Pi-Mei Wei²; Shu-Hua Hsieh²; Ms. Huang-Ju Chi³ and Chi-Pei Wei², (1)Chang Gung Dementia Center, Taoyuan Chang Gung Memorial Hospital, Taoyuan City, Taiwan, (2)Chang Gung Dementia Center, Taoyuan, Taiwan, (3)Dementia Center, Taoyuan Chang Gung Memorial Hospital, Taoyuan, Taiwan

Abstract:

Chang Gung Dementia Center, founded in 2009, is located in the northern Taiwan, as a part of one of major medical centers. It is designed for the following purposes:

- It is a place for Memory Clinics.
- Researches and Phase III Clinical Trials are performed.
- It provides direct or indirect care supports to affiliated nursing institutes.
- It provides non-pharmacological treatment to the people with dementia (PWD).
- It provides support and educations to the caregivers.
- It works as a venue for professional training for multidisciplinary teams.
- It provides public and societal education, including prevention and screening.

The Center consists with the clinics, a therapeutic area and a daycare unit, measured 985 m². In the clinics, a multidisciplinary team works for the model as in Figure 1. Physicians with dementia specialties include neurologists, psychiatrists, geriatricians, and rehabilitative physicians.

Particularly in this model, case managers (CM) perform the evaluation for PWD with an initial visit before a physician visit. After the visit, CM also gives education and counseling for PWD and their family caregiver (FCG). For the follow-up visits, FCG evaluate PWD and FCG right before the physicians if the clients have any particular event or question after the last visit. CM usually can give suggestions to the clients and also to the physicians so that the visit can be facilitated with better efficacy.

In the therapeutic areas, nonpharmacological programs are given to PWD, including School of Wisdom, Music Therapy Programs and Reminiscence. In addition, supportive groups and care skill classes are given to FCG in this place. There is also Educational Showroom dedicated as a walking-in educational tour and reading materials, where the students can learn a basic knowledge in one hour.

In the daycare center, people with very mild and mild dementia are eligible for the admission. They utilize the facility on a day-by-day basis, however, not necessarily daily. The environment is quipped with bright modulation simulating sunlight (according to a clockwise change in brightness and color temporal).

In this center, physicians (including neurology, psychiatrics, rehabilitation and geriatrics) work closely with nursing specialty, case managers, occupational therapist, nurse aides, social workers, and neuropsychologists in one are within the hospital.

Particularly case managers are trained to give consultation intensively PWD, their FCG and all the professionals regarding dementia care. Most of the services are delivered during the clinic time. The management flow in the memory clinics is efficient and results high throughputs. This model service a paradigm of dementia care, linking clinical/medical care to community needs of the people living with dementia. It is also a place for educational purposes.

Figure 1. Dementia Clinic with multidisciplinary team





POSTER ABSTRACTS

Models of care - Poster

P14-012

TIMESLIPS AND THE CREATIVE CARE REVOLUTION

Susan H. McFadden*, Psychology, University of Wisconsin Oshkosh, Oshkosh, WI

Abstract:

TimeSlips is evidence-based, award-winning, and person-centered. Its goals are to inspire people with dementia to hone and share the gifts of their imagination; inspire others to see beyond memory loss and recognize the strength of people with dementia; build creative communities of care that engage elders, volunteers, staff, and families; and to work to make creative engagement standard practice in care settings for people of all ages and abilities. *TimeSlips* has certified facilitators in 12 countries and 42 states offering creative engagement programs in care settings, senior centers, memory cafes, museums, libraries, and schools. This presentation will introduce attendees to the link between person-centered care and creative engagement, and will assert that life in long-term care can be a time and place for growth. It will review research on *TimeSlips* that shows how it can improve the quality and quantity of interactions between staff and residents, improve attitudes toward people with dementia, improve affect and communication among people with dementia, and increase meaningful social engagement in long-term care settings.





POSTER ABSTRACTS

Models of care - Poster

P14-014

THE ENABLING HOUSEHOLD – A NEW APPROACH TO DAY CENTRE CARE

Marlene Grogan, Education & Consultancy, Alzheimer's WA, Perth, Australia and **Jason Burton***, Alzheimer's WA, Perth, WA, Australia

Abstract:

There has been a growing recognition that the traditional model of day respite for people living with dementia does little to support a reablement and wellness approach. Traditionally the day service model has been built on the concepts of entertainment and large group activity. The clients are seen as passive recipients of the day centre experience, meals are prepared and served up, entertainment in the form of games, quizzes or crafts fill the day, activities are scheduled and there is little emphasis on the individual or on activities that are meaningful to the individual.

The Australian Government has adopted a wellness and reablement approach as part of its policy for the delivery of community care services. These approaches can be described as:

- *Wellness involves building on the strengths and goals of individuals to promote independence in daily living tasks.*
- *Reablement involves short-term interventions to adapt to functional loss or to regain confidence and capacity.*

Adapting these approaches for people with dementia that incorporates a person centred care philosophy and the domains of wellbeing holistic care approach has been the focus of the development of a new model for day centre services in Western Australia.

Alzheimer's WA has developed and implemented an Enabling Household™ model for day centre services. The model takes a dementia specialist approach to transforming the day centre service into a modern person centred environment that focuses on enablement and wellness of the person with dementia. The model has been developed and implemented across Alzheimer's WA's three dementia houses in metropolitan and regional West Australia. Following the success of the models implementation, Alzheimer's WA has been working with ten other day centres to support their transformation utilising this approach.

Moving beyond the traditional medical stages model of 'managing dementia', it takes a revisionary approach to psycho-social needs of the person, their experiences, abilities and the impacts of cognitive impairment. The transformation of care is through a change management approach that supports implementation of research based best practice dementia care

The Enabling Household™ model is a journey that honours what is working well, what can be different with the household model trajectory supporting services to journey through change, growth and development.

Demonstrating key improvements in staff retention and satisfaction the model provides a work environment that engages and fulfils staff needs.

This presentation will describe the change process undertaken to move from a traditional task focused service into a person centred Enabling Household™ model. It will explore the staff's journey of change, outcomes for household members living with dementia and their carers, and the refurbishment of the physical environment to support the models implementation.



POSTER ABSTRACTS

Models of care - Poster

P14-015

“PERFECT TEN”: AN INTEGRATED DEMENTIA CARE MODEL COMBINING MEDICAL AND SOCIAL CARE IN TAIWAN

Prof. TsuAnn Kuo*, Medical Sociology and Social Work, Chung Shan Medical University, Taichung City, Taiwan; Po Ku Chen, Integrated Chinese Medicine and Medicine, Chung Shan Medical University Hospital, Taichung City, Taiwan; Hsi Hsien Chou, Center for Integrated Dementia Care at Taichung City, Chung Shan Medical University Hospital, Taichung, Taiwan and Chien-Ning Huang, Hospital Administration, Chung Shan Medical University Hospital, Taichung City, Taiwan

Abstract:

Objective: Currently, 270,000 people have Dementia in Taiwan and the majority of people with Dementia are cared for by a limited number of family caregivers. The purpose of this paper is to evaluate a new model called “Perfect Ten” that integrates medical and social care for people with Dementia in Taiwan. The objectives are: (1) to demonstrate how care managers and 10 different types of professionals work together to design care plans; (2) to evaluate the results of the care quality combining both medical and community-based care resources from the eyes of the Dementia families.

Method: Action Research and Qualitative Interviews were conducted to collect data from three sources: the professionals, the care managers, and the Dementia families. A total of 430 Dementia patients were served in 2017 and about 20% of the Dementia families fully utilized the “Perfect Ten” service. The Dementia families would attend pre-arranged sessions where professionals from ten disciplines (medical doctors, Chinese medical doctors, nurses, nutritionists, physical therapists, occupational therapists, pharmacists, psychologists, social workers, and lawyers) can provide free consultations, education or care tips for the Dementia patients or their family members. Six months later, the Dementia families were interviewed to explore how the “Perfect Ten” model affected the condition of the Dementia patient and their own care situations.

Result: Compared with the entire 430 pool of patients, the people who used “Perfect Ten” service were caregivers with complicated care situations or lack of skills to take care of their Dementia members. The demographic characteristics of the Dementia patients were 82 on average, 70% female and had different types of diagnosis and degree of severity. Based on the interview results, the professionals who joined the “Perfect Ten” model revealed that they were able to learn how Dementia affected the individuals and their families from the “Patient-centered” perspective; and how professionals can work together to care better for the Dementia families. The results from the Dementia families showed that more families were willing to help as a result of better understanding of care from the advice of the professionals, more knowledge and support gained from the care managers, more utilization of the informal and formal resources to help them take control of the care situations, and more empowered to have a direction to face the future.

Conclusion: The initial evaluation of the “Perfect Ten” showed that positive outcomes were revealed among medical professionals, care managers, and Dementia families. This qualitative outcome showed that families needed a knowledgeable and accountable team of professionals to support and answer questions. The cost to the ten professionals was minimal, from 4 to 8 hours per month, but the impact to more than 100 Dementia families signified stable conditions and less caregiver burn-outs. This model can be further evaluated by several performance indicators such as hospitalization rate, emergency rate, falls, caregiver burnout or condition worsening due to lack of physical and nutritional care. The model also can be promoted because it integrates both medical and social care by forming a Support Network around the Dementia families. As Taiwan heads for its second decade of the national Long-term Care Plan 2.0, the benefits of such model can be replicated to combat the increasing number of Dementia population and caregiving needs.



POSTER ABSTRACTS

Models of care - Poster

P14-016

ALZHEIMER'S JOURNEY COORDINATOR: IMPROVING LIVES, REDUCING HEALTH DISPARITIES

Laura Jakimowicz*, Rowan University/Rutgers-Camden Board of Governors (RURCB OG), James J. Florio Center for Public Service, Camden, NJ and Mrs. Mary Michael, Patient Advocacy and Stakeholder Management, Otsuka America Pharmaceutical, Inc, Princeton, NJ

Abstract:

The complex, multi-layered nature of the U.S. healthcare system is very difficult to navigate for people with dementia, their families, and their care partners. Low-income populations face even greater challenges brought by social, economic, linguistic, and cultural barriers. As the Alzheimer's disease community prepares for new therapies to reach people with dementia, our most immediate opportunity is to help people affected by dementia to navigate their Alzheimer's journeys and take full advantage of the resources available to them.

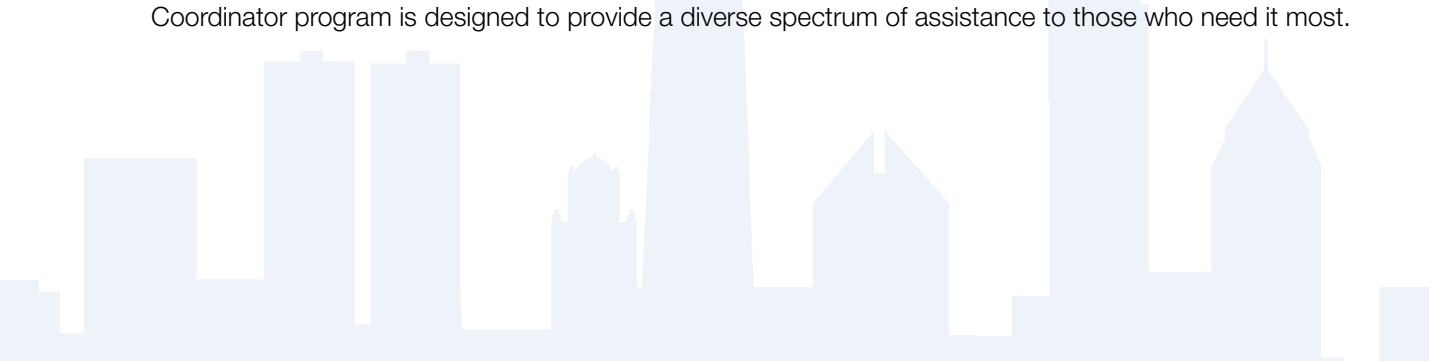
To this end, Rowan University/Rutgers-Camden Board of Governors (RURCB OG) collaborated with various organizations, including Otsuka America Pharmaceutical, Inc., to launch the first-ever academic certification in Alzheimer's Journey Coordination in Camden and surrounding areas in south Jersey (USA). Alzheimer's Journey Coordinators provide non-medical support to people with dementia, as well as their family and carers, and they act as the "missing link" in the healthcare system and along the care continuum. Alzheimer's Journey Coordinators serve a variety of roles; they act as navigators, provide scheduling assistance, and arrange for transportation; they educate about the Alzheimer's journey and serve as a trusted advisor connecting families to resources, services, and community programs.

The Alzheimer's Journey Coordinator program was inspired to launch following the success of Patient Navigation programs in oncology and other chronic disease areas. In particular, it followed some of the "best practices" established following Dr. Harold P. Freeman's pilot program to help women in Harlem gain better access to care and treatment for breast cancer. Over five years, Dr. Freeman's Patient Navigation program increased survival rates from 39 percent to 70 percent and generated consistently high satisfaction rates from women in the program.

In Camden, New Jersey, where more than 20 percent of seniors live below the poverty line, the Alzheimer's Journey Coordinator role has a similar opportunity. Alzheimer's Journey Coordinators have a nuanced understanding of the socioeconomic of the community, and they are in a unique position to provide appropriate assistance to people with dementia, their families, and their carers.

The Alzheimer's Journey Coordinator program is being launched in Summer 2018. The inaugural training program will kick off at Camden County College, with a one-year certificate program. The program will be taught over a six-month period, alongside an externship within local communities. Upon completion, the program will place graduates into healthcare institutions across New Jersey as Alzheimer's Journey Coordinators.

As the Alzheimer's community waits for the next "breakthrough" therapy, the imperative we all face is to create practical, implementable solutions to improve the lives of those affected by dementia. The Alzheimer's Journey Coordinator program is designed to provide a diverse spectrum of assistance to those who need it most.





POSTER ABSTRACTS

Models of care - Poster

P14-017

IS THERE EQUITY IN INITIAL ACCESS TO FORMAL DEMENTIA CARE IN EUROPE? THE ANDERSEN MODEL APPLIED TO THE ACTIFCARE COHORT

Liselot Kerpershoek^{*}, Department of Neuropsychology and Psychiatry, Maastricht University, Maastricht, Netherlands

Abstract:

Objective: Services should be equally available for those who have the same needs. Possible reasons for inequality arise from differences in availability, quality, costs and information for different population groups. In the current study the Andersen model is used to evaluate whether there is equity in access to dementia related formal care services.

Method: People with middle-stage dementia and their informal carers (n=451) from eight European countries were included. At baseline, there was no use of dementia related formal care yet, but people anticipated using formal care within the next year. Logistic regression analyses were carried out with each of four clusters of service use as dependent variables (home social care, home personal care, day care, admission). The independent variables (predisposing, enabling and need variables) were stepwise added to the regression in blocks.

Result: Disease severity, a higher sum of (un)met needs, more hours spent on informal care and living alone at baseline significantly predicted the use of home social care and home personal care at six months and one year follow-up. The predisposing variables age of the person with dementia and region of residence significantly predicted home personal care use. A higher sum of met needs, living alone at baseline, having a female informal carer and Northern region of residence predicted use of day care at follow-up. Disease severity, more hours spent on informal care, the person with dementia being male and Northern region of residence significantly predicted admission to a nursing/care home at follow-up.

Conclusion: The Andersen model can be applied to dementia care, and it provided the insight that besides need factors the predisposing variables region of residence, gender and age do play a role in care use. In addition, it indicated that the numbers of hours spent on informal care, living alone, needs and disease severity are important predictors for formal care use. Care professionals should pay attention to these predisposing factors to ensure that they do not serve as barriers for those in need for care.



POSTER ABSTRACTS

Models of care - Poster

P14-018

CHANGING THE RHYTHM OF THE DEMENTIA CARE

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Abstract:

This paper will discuss the power of music to change the rhythm of dementia care. Three music initiatives conducted in the UK over a 5 year period will be compared. The first an orchestra composed of symphony orchestra musicians, people with dementia living in the community and their care partners. The second a care home band project designed to include people with dementia living in care home settings in the creation of care home bands comprising care home residents with and without dementia, care home staff, family members and other community visitors. The third a music cafe where professional musicians perform interactively to an audience of people living with dementia and their care partners who remain living in their own homes. All three initiatives have used music as a mechanism to change the rhythm of care provision and to challenge negative perceptions of dementia.

Objectives: 1. To promote and enhance the well being of those living with dementia through musical activities.
2. To raise awareness of dementia and tackle stigma in general public perceptions of dementia.

Method: Methods of data collection to meet the first objective are: Multi-methods designed to elicit the views of people living with dementia, musicians and care partners. These include structured and unstructured observations, interviews and evaluation questionnaires.

Objective two - questionnaires for those viewing the performances to share their perceptions of dementia pre and post viewing public performances.

Result: The data demonstrate four thematic findings. That each initiative 1. promotes social inclusion and positive interactions; 2. provides opportunities for life long learning; 3. creates an environment conducive to peer support and 4. enhances and maintains positive social identity.

Objective 2: viewing performances of people living with dementia directly challenges negative perceptions of dementia and promotes an awareness of the abilities of those living with dementia and thereby challenges the stigma surrounding dementia.

Conclusion: Music has huge power to change the rhythm of dementia care provision and to promote well being for those living with dementia. Viewing performances of those living with dementia challenges negative perceptions and the underpinning stigma that continues to pervade dementia discourse.





POSTER ABSTRACTS

Models of care - Poster

P14-019

THE OPTIMAL PATHWAY TO DEMENTIA CARE: A QUALITATIVE STUDY BASED ON EXPERIENCES AND ATTITUDES OF 85 PEOPLE WITH DEMENTIA AND THEIR INFORMAL CARERS IN EUROPE

Liselot Kerpershoek, Department of Neuropsychology and Psychiatry, Maastricht University, Maastricht, Netherlands

Abstract:

Objective: This qualitative study is part of the Actifcare study, and investigated experiences, attitudes, barriers and facilitators concerning (access to) formal care use. The Actifcare study looked at ways to improve access to home and community-based dementia care, in order for people to receive the right amount of care when and where needed.

Method: 85 semi-structured in-depth interviews were conducted in eight European countries. The five themes were 'Receiving the diagnosis', 'Attitudes towards formal care', 'Tension between independence and acceptance of care', 'Exchanging views within the family', and 'Cooperation with health care professionals'. With qualitative analyses codes and categories were identified.

Result: Having one contact person to guide and support you is crucial. Adequate information about dementia and available resources should be distributed immediately after the diagnosis. Services should be as tailor-made and adjusted to a person's needs. It is helpful to have an open attitude towards care, and to feel that it is justified that you make use of formal care services. In addition, it is important to involve your social network as they can take on caregiving tasks. It is helpful to have a diagnosis (in most countries). Concerning decision-making, involvement of others beyond the immediate dyad was helpful in a few instances, but was not a major influence. The person closest to the person with dementia is the most important one in decision-making; this person should thus be supported by e.g. healthcare professionals.

Conclusion: The results can be summarised in a positive flowchart, representing the optimal pathway for access to care. Overall, there are fixed factors that cannot be changed, such as disease-related factors and system-related factors. If these factors are present as described here, they aid in finding access to care. Health care professionals should pay attention to these factors to ensure optimal access to care.





POSTER ABSTRACTS

Models of care - Poster

P14-020

STEPS FOR CREATING AN INNOVATIVE AND LIFE-AFFIRMING DEMENTIA PROGRAM: THE PLAZA ASSISTED LIVING'S HALI'A EXPERIENCE, HAWAII

Mr. David Troxel¹; Tricia Medeiros²; Celeste Saquing³; Lisa Skelton⁴ and **Jan Ka'aina**², (1)Best Friends Approach, Sacramento, CA, (2)The Plaza Assisted Living, Honolulu, HI, (3)The Plaza Assisted Living, Mililani, HI, (4)Sound Health Hawaii, LLC, Honolulu, HI

Abstract:

The presenters will share their experience and findings from a two-year initiative to create an innovative, relationship centered, activity rich, residential dementia care program. Specific topics will include program visioning and design, innovative staff training, community education, marketing to find an audience for your dementia program including web content, and innovative graphics/poster design to build awareness. Evaluation efforts and sustainability will also be discussed. Participants will leave with a tool kit/check list to allow them to apply lessons learned to any dementia program including program development and marketing recommendations.

The goals of the project were to:

- Introduce an innovative and activity rich dementia program to 5 dementia care assisted living communities on the island of Oahu in Hawaii.
- Create a program that is rich in local tradition and one that reflects the multicultural nature of the community with its rich melting pot of communities including native Hawaiian, Japanese, Filipino, Korean, and other cultures.
- Utilize contemporary language in its description of dementia and persons living with dementia.
- Embrace life-affirming programming including the Best Friends Approach to Dementia Care.
- Develop innovative training including Master Trainers at each community, innovative staff workbooks and self-guided learning along with traditional classroom style learning.
- Develop interesting activities that reflect formal, structured time as well as informal engagement.
- Create staff buy-in to this new program stressing the person over the task vs. the task over the person which is often the case in residential care.
- Roll out compelling marketing pieces and educational programming.
- Build a program that can be evaluated on an ongoing basis and be sustainable over an extended period.

The presentation will discuss the process of our initiative including:

An initial, day long "dementia care boot camp" with key stakeholders. This included staff members who would be working in the program as well as program leadership.

Creating a program name, Hali'a which in the Hawaiian language can be translated as "cherished memories."

Committees were assigned including a committee focused on programming, one on health care, one on education and marketing, and one on staff training.

A project leader was named, and program consultant hired.

Timelines were developed with monthly objectives and goals, and opportunities for celebration along the way.

Key staff members were trained in the Best Friends philosophy and to become Master Trainers to teach others.



POSTER ABSTRACTS

Committees met regularly, and the entire project work group met monthly in person or with teleconferences.

Educational materials, marketing materials and posters highlighting key elements of the program were created.

Staff were given initial orientation and a self-study/group study work book to accompany an ongoing set of classes.

Life story forms were developed and completed on each resident in memory care.

The programming group met regularly to innovate in activities and engagement.

Results: The Hali'a memory care program in five assisted living residential communities is now fully operational and results show that the programming and contemporary vision has been well received by persons living with dementia, their care partners and referral sources/professionals in Oahu.





POSTER ABSTRACTS

Models of care - Poster

P14-021

WHEN 'NORMAL' IS RADICAL: DEVELOPMENT OF A RESIDENTIAL FACILITY FOR PEOPLE WITH DEMENTIA THAT SEEKS TO PROVIDE A FAMILIAR AND MEANINGFUL LIFE FOR PEOPLE WITH DEMENTIA

James Vickers^{*1};Corinna Dwan²;Lucy O'Flaherty³ and Liz Thomas³, (1)Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, TAS, Australia, (2)University of Tasmania, Hobart, Australia, (3) Glenview Community Services, Hobart, Australia

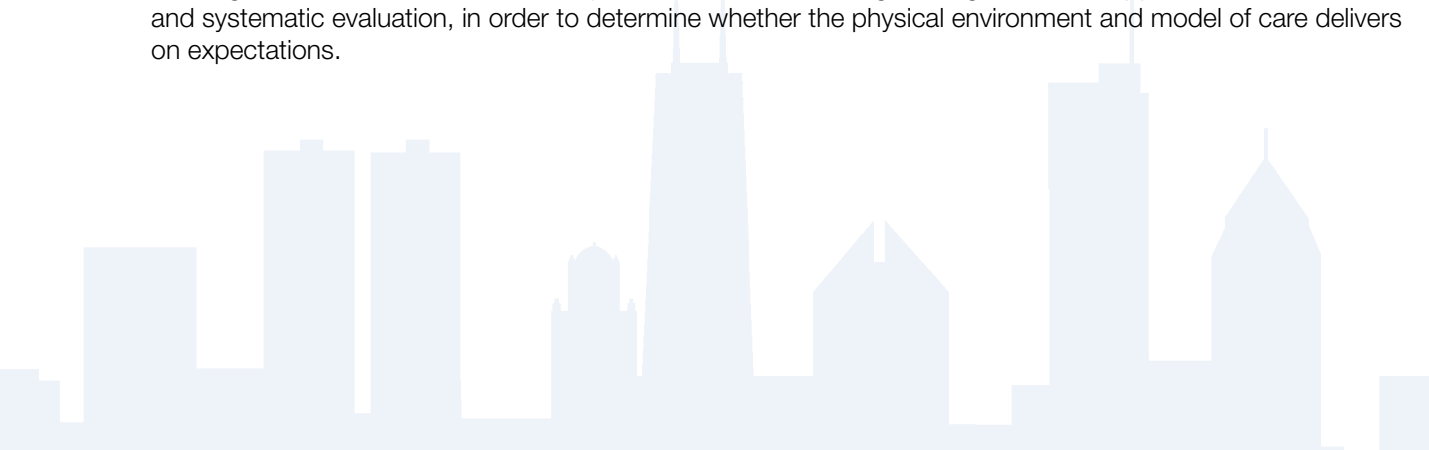
Abstract:

It is increasingly recognised that the physical infrastructure of residential facilities and models of care for people with dementia is not fit for purpose, particularly in providing people with dementia opportunities to continue to live meaningful lives. In Tasmania, Glenview Community Services has obtained financial support to construct a residential village on a greenfield site that will be designed to advance the quality of care for people with dementia. The 'Korongee' village project involves a deep partnership between Glenview and its local community, architects (ThomsonAdsett) and academics (University of Tasmania), to provide a design that seeks to provide residents with a familiar environment and lifestyle in line with the vernacular of the community in which they have resided, as well as a model of care that emphasises agency, person-centred care and meaningful activities.

The Korongee development will consist of 11 single story houses (8 residents each) that are interconnected in clusters, designed along the lines of the Australian suburban cul-de-sac. The clusters of homes will be centred around a central greenspace and plaza, consisting of a café, general store and cinema. The external environment will also comprise of architectural cues and clear line of sight, in order to assist residents with wayfinding and decision-making.

The centre of home life will comprise of typical Australian living and kitchen facilities, with interior features based on the latest evidence related to dementia design. Individual homes will also be designed to be reflective of six different lifestyle typologies that have been identified based on shared values, attitudes and behaviours of the Tasmanian population. Each resident will be matched to a home most reminiscent of their personal history using a lifestyle questionnaire. By grouping people with similar background history, values and interests together within a home, there is the expectation of greater compatibility and social connectedness.

Residents will be supported by suitably trained 'homemaker' staff, with most daily activities, such as meals and bathing, to fit the resident's schedules and with residents involved in decision-making as much as they may choose to be. The focus will be on supporting residents to have meaningful lives, that are also familiar with respect to their personal biography, and centred on their abilities and interests, supporting connections to the local community, their families and friends. The Korongee facility will also be a learning organisation, committed to contemporary approaches to dementia care based on the best available evidence. In partnership with the Wicking Centre, based at the University of Tasmania, the Korongee village will also support a culture of research and systematic evaluation, in order to determine whether the physical environment and model of care delivers on expectations.





POSTER ABSTRACTS

Models of care - Poster

P14-023

MODELS OF CARE FOR PEOPLE LIVING WITH DEMENTIA IN ACUTE HOSPITAL WARDS: RESULTS FROM AN ETHNOGRAPHIC STUDY

Katie Featherstone Dr*, School of Healthcare Sciences, Cardiff University, Cardiff, United Kingdom and Andy Northcott Dr, School of Allied Health Sciences, De Montfort University, Leicester, United Kingdom

Abstract:

Objectives There is increasing recognition that action is required now to improve the experience and outcomes of people living with dementia on admission to acute hospitals for an unrelated condition (NICE and SCIE, 2006; NAO, 2007; House of Commons, 2008; Department of Health, 2009; Health Foundation, 2011). In the UK, concerns persist about poor treatment, neglect, abuse, and discrimination of older people in acute hospital (House of Lords, 2007; Francis report, 2013), with widespread poor care identified (Alzheimer's Society, 2016). People living with dementia are a highly vulnerable group within the acute hospital setting, their functional abilities can deteriorate significantly (Goldberg et al, 2012) and have markedly higher, short-term mortality (Sampson et al, 2009).

Models of care for this patient group have typically assumed that the principles of good care that have been integrated into long-term facilities can transfer unproblematically into other settings (Moyle et al, 2008), however, the acute setting has markedly different organizational structures, cultures and goals. Little is known about the ways in which the current models of care within the acute setting impact on people living with dementia.

Methods In response, this paper draws on empirical findings of an in-depth ethnographic study in 10 wards within 5 hospitals across England and Wales, purposefully selected to represent a range of hospitals types, geographies and socio-economic demographics. Across these sites 155 days of observational fieldwork were carried out in areas of acute hospitals known to admit large numbers of people living with dementia for an unrelated acute condition: Trauma & Orthopaedic wards and Medical Assessment Units. Approximately 600,000 words of observational fieldnotes were collected, transcribed, cleaned and anonymised, 436 ethnographic interviews conducted in the ward, taken from 155 participants including ward staff, carers and patients themselves. Detailed case studies were also conducted with 10 people living with dementia, observing their care at the bedside and speaking to the person and their family and carers throughout their admission.

Results We identified extremely high levels of resistance to care amongst people living with dementia within acute hospital wards. It was a common feature of ward life; every person living with dementia we observed admitted within the acute hospital ward resisted care at some point during our period of observation. Importantly, resistance, in whatever form it manifested, was always interpreted by staff as a feature of the person's dementia diagnosis, signified a person's lack of capacity, and as such interpreted as a behaviour to be overcome or managed. However, our observations identified that resistance was typically a response by people living with dementia to the models of care within the wards (fixed routines and timetabled demands), and the ways in which ward staff delivered care at the bedside. In response, ward staff used multiple interactional approaches that focussed on reminding the person of the 'rules of the ward'. However, fitting people living with dementia within these models of care routinely involved containing and restraining the person at the bedside or in the bed.

Conclusion We show the emotional and somatic impacts of these models of care for people living with dementia and the ways in which these models of care had detrimental consequences for people living with dementia, their families, and for ward staff.



Education and training of the workforce - Poster

P15-002

CAPER DEMENTIA METHODOLOGY: CHANGING THE CULTURE, CHANGING THE CARE IN UK ACUTE HOSPITALS

Danielle Wilde^{*}, Royal Free London NHS Foundation Trust, London, United Kingdom

Abstract:

There are more than 850,000 people living in the United Kingdom with a diagnosis of dementia. At any one time, 6% of those people will be an inpatient in an acute hospital, occupying 25% of all hospital beds across the National Health Service.

In spite of how prevalent dementia is in acute hospitals and how frequently healthcare professionals work with these patients, the clinical outcomes for people living with dementia remain poor. If you are admitted into hospital and you have a diagnosis of dementia, you are;

- more likely to die,
- more likely to stay in hospital longer (up to seven times as long),
- more likely to experience a fall,
- increased confusion and
- more likely to end up in institutional care

In 2013, the Royal Free London NHS Foundation Trust sought to address this issue by running a pilot study in conjunction with the Health Foundation. This project established a dementia specialist Occupational Therapy post designed to case-find and key-work some of the most at-risk patients with dementia admitted to hospital.

The results from this 18-month project were compelling;

- 154 patients seen
- Reduced average length of stay by 2.6 days
- Reduced readmissions by 26%.
- 34% avoided long-term placement

However, we discovered some unanticipated outcomes that surprised us.

- Staff working alongside the dementia specialist OT felt less skilled
- Increase in inappropriate referrals

We completed a process map of the care received by a patient under the dementia specialist OT project and identified the key components of the care pathway. From the piece of work, we created CAPER; the UK's first acute hospital methodology for caring for patients with dementia in this setting. CAPER stands for the following;

C: Collateral information and specialist communication

A: Assessment

P: Partnership

E: Enabling

R: Role-modelling

Our experiences with the dementia specialist OT role showed us that results, however positive they seem, are limited when you only address the anatomy of care; how services look and are configured. With CAPER,



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we tried to tackle the physiology of a hospital ward; how behaviour and culture informs the care that is then delivered. Traditionally, dementia education programs recruit senior clinicians, take them off for a day of powerpoint and hope that when they next work a shift, some of what they've seen in the classroom will translate into practice. For this reason, those of us who teach regularly are resigned to the fact that teaching doesn't always work, at least not in the way we hope it will. When I was thinking about how to deliver the CAPER method, I started to notice that the staff who spend most face to face time with the patients; the housekeepers, junior nurses, domestics and nursing assistants are the same staff who have limited or no access to training.

We conceived a 5 week course consisting of 5 one hour sessions delivered to these staff groups on the wards. The modules were practically focussed and introduced tools which were then completed with a mentor between sessions. The results have been excellent;

- Confidence and competence amongst junior staff significantly improved
- Democratised "expertise" on the ward
- Improved clinical outcomes for patients
- Established care leadership at all levels
- Improved quality of interactions between staff and patients across the board

In hospitals, many of the problems patient's experience stem from the over-medicalisation of dementia. CAPER reframes kindness and friendship as clinical interventions and shows that you don't have to be the boss to be a leader.





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Education and training of the workforce - Poster

P15-003

EXPLORING DEMENTIA ATTITUDES AMONG HEALTH CARE AND SOCIAL SERVICE PROFESSIONALS USING THE DEMENTIA ATTITUDES SCALE (DAS)

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Abstract:

Objective: Scarce information exists about attitudes of dementia care professionals although positive attitudes of professionals towards persons with dementia (PWDs) translate to better quality care for PWDs. ¹ To enhance effectiveness of dementia training and education for these professionals, further consideration of attitudes among dementia care professionals is needed. Using the Dementia Attitudes Scale (DAS), ² this descriptive study examined and compared health care and social service professionals' knowledge and comfort levels in serving PWDs.

Method: In developing a multi-sectoral initiative to build "dementia capable" environments in Wisconsin, this cross-sectional assessment involved 78 health care and social service professionals that participated in local and statewide dementia care workshops in 2017. These professionals completed a baseline survey that included questions on demographics, position title, years of experience, previous dementia-specific training received, and the DAS. Group differences were assessed through Mann-Whitney U tests and Spearman correlations. The institutional review board reviewed and deemed this study exempt as a program evaluation / quality improvement project.

Result: This cohort was mostly Caucasian (92.4%), female (91.1%), and 58.9% worked 5 years or less in their current positions. Most professionals (67.6%) received previous dementia-specific training before completing their recent workshops. The baseline mean knowledge level of these professionals was high (M=65.2 of 70, 93%), whereas the comfort level was lower (M=57.5 of 70, 82%). The least positive attitudes related to comfort level appeared in the professionals' avoidance of agitated PWDs, frustration in not knowing how to help PWDs, and inability to imagine taking care of a PWD.

Compared with professionals who reported no previous training, those who received previous dementia-specific training had higher knowledge (median=65 vs. 68 respectively, $p=.012$) and comfort levels (median=56 vs. 62 respectively, $p=.008$). These differences appeared significant regardless of the professionals' years of experience; knowledge and comfort levels were not significantly correlated with years of experience ($p>.05$ for both). No significant differences emerged in overall knowledge level nor indicators between health care and social service professionals. Only one significant difference between the two groups was identified among the comfort indicators; health care professionals reported significantly less familiarity with Alzheimer's Disease and related dementia than social service professionals ($p<.05$).

Conclusion: This analysis illustrates how the DAS can be used to identify specific attitudes of health care and social service professionals to address in dementia-specific training. Further, it shows that dementia-specific training may play a more important role than years of professional experience in shaping attitudes and comfort level of professionals working with PWDs.

References:

¹ Travers, C. M., Beattie, E., Martin-Khan, M., & Fielding, E. (2013). A survey of the Queensland healthcare workforce: attitudes towards dementia care and training. *BMC Geriatrics*, 13, 101. <http://doi.org/10.1186/1471-2318-13-101>

² O'Connor, ML & McFadden, SH. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*, 2010, doi:10.4061/2010/454218.



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Education and training of the workforce - Poster

P15-004

ENHANCING “DEMENTIA CAPABLE” EMERGENCY MEDICAL SERVICES THROUGH FRIENDLY VISITORS

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Abstract:

Few interventions utilize emergency medical service (EMS) personnel for carrying out support initiatives for persons with dementia (PWDs) living alone without ongoing social services or case management. In addition, limited efforts have been made to assess the needs of professionals serving PWDs and develop effective approaches for building skills and reducing gaps in education.¹ Through an academic-community collaboration with a local EMS agency in Southern Wisconsin, this pilot EMS Friendly Visitor program proposes to extend the length of home residency for PWDs living alone by connecting them to social services. This presentation will explain the progress in developing this community-based program.

As the first stage of development and implementation, EMS professionals completed a pilot three-session training that included dementia basics, motivational interviewing, and basic knowledge on case management services. Seventeen EMS professionals participated in the training including paramedics, administrators, and associated staff. This cohort was predominantly Caucasian (94.1%) with an almost even distribution of male and female professionals (52.9 vs. 47.1% respectively). These professionals worked in their current positions for an average of 10.82 years (range from 2 weeks to 25 years). Pre-training and post-training evaluation surveys assessed dementia knowledge, attitudes regarding PWDs, and self-efficacy to care for PWDs. EMS professionals also answered qualitative write-in questions about suggestions for future training.

Dementia knowledge significantly increased from pre- to post-training in several areas, including identifying common triggers for behaviors associated with dementia ($p < .05$), explaining communication changes for PWDs throughout the course of dementia ($p < .05$), and identifying strategies for communication at each stage of dementia ($p < .001$). Self-efficacy in working with PWDs significantly increased in the ability to apply at least one motivational interviewing strategy for use with PWDs ($p < .05$) and to employ the core skills of motivational interviewing at a basic level with PWDs ($p < .05$). Professionals favored training on using active reflective listening with PWDs, engaging PWDs at different stages of the disease. Suggestions included more active role-playing on potential dementia scenarios that could occur with PWDs and training involving simulation environments.

These results indicate improvement in dementia knowledge and improvements in attitudes toward PWDs through education on dementia basics and motivational interviewing and justify the critical need for continuing to enhance education and skill building for EMS professionals to work with PWDs. Based on these results, future directions for education and program development will be discussed.

References:

¹ Surr, CA & Gates, C. (2017). Effective dementia education and training for the health and social care workforce: A systematic review of the literature. *Review of Educational Research*, 87(5), 966-1002.



POSTER ABSTRACTS

Education and training of the workforce - Poster

P15-005

THE EFFECT OF STRESS MANAGEMENT PROGRAM AMONG DEMENTIA CARE WORKER

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Abstract:

Objective: Stress management is important for dementia care staff because their mental health condition is chronically worsening. The aim of this study was to develop the Stress Management Program which focuses on four themes; 1) sleep hygiene, 2) time management, 3) communication skills, and 4) coping skills of behavioral and psychological symptoms of dementia (BPSD), and to investigate the effect of the program on mental health outcomes for dementia care staff.

Method: We developed this program based on previous findings and the exchange of opinions among professionals, such as clinical psychologists and certified care workers. This program consisted of four sessions regarding each theme and focused on individual work and group discussion rather than short lectures, which are influenced by the lecturer's teaching skills. Moreover, we also developed PowerPoint slides and a user manual for the program to enhance general versatility. A survey was conducted targeting 60 staff members at 11 facilities in Kinki, Japan. We divided participants into 2 groups (intervention and control groups) and asked them to complete the questionnaire at baseline, post-intervention, and follow-up. A clinical psychologist who was not involved in the study design conducted the stress management program. The intervention was conducted in one day and the duration of each session was 90 minutes. The 12-item version of the General Health Questionnaire (GHQ) was employed to evaluate the mental health condition.

Result: The total of 49 participants (25 staffs in the intervention group, 24 staffs in the control group) were analyzed. Although a two-way analysis of variance (group (2) × time (3)) revealed that the GHQ scores in the intervention group tended to improve post intervention ($t(24) = 2.38, p = 0.077$), the effect of the intervention disappeared at follow-up. At follow-up, 6 staff members (24%) had continued their individual work of the four sessions they practiced during intervention. Of these, 4 (67%) had improved their mental health. Of the 19 staff members who had discontinued the individual work, 5 (26.3%) had improved their mental health. However, according to Fisher's exact test, regardless of whether participants continued the individual work or not, there was no a significant difference in the improvement rate (67% versus 26.3%, odds = 5.17, 95% CI = 0.55-74.2, $p = 0.14$).

Conclusion: We concluded that the Stress Management Program can be effective in improving mental health for dementia care workers; however, constructing a support system containing work that the staff can continually practice is also needed.



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P15-006

A MODEL FOR INCREASING STAFF COMPETENCIES IN DEMENTIA CARE THROUGH AN INTERDISCIPLINARY AND CROSS-SECTIONAL CLASSROOM

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Abstract:

Objective: In Denmark there is a general lack of coherence in content, quality and publications of effects of the methods used in health care and social work with people with dementia and their relatives. The Danish Government wants to raise and strengthen the quality in dementia care by collecting and publish knowledge about practice in this area as well as promote the methods known to be efficient (Ministry of Health and Elderly 2016).

The Danish Dementia Action Plan for 2025 points at a pronounced need for increasing competencies among staff working in the area of dementia. The Action Plan especially stresses the need for focusing on implementation of best practice in daily work (Ministry of Health and Elderly 2016).

The objectives of this research project is to increase staffs' competencies and to support and promote an inter-disciplinary and cross-sectional collaboration culture among staff (nurse helpers, nurses, therapists, social workers and General Practitioners) working with persons suffering from dementia illnesses. Moreover, to increase knowledge and understanding about people with dementia and their relatives, and how to collaborate with a person-centred care perspective. **Method:** Method: Approximately 200 staff members from 17 municipalities in Denmark will participate in a one-week course targeting one of three levels of education between March 2018 and March 2019. In addition to this, all participants and all levels of education will meet and work together in two conferences and a seminar during the course period. The function of these "meeting places" are to support the aim of promoting the inter-disciplinary and cross-sectional collaboration culture.

Data will be collected through qualitative observations and interviews. Observations will be done during educational sessions and conferences and interviews will be carried out with staff members following the course as well as with managing staff in hospitals and municipalities. The steering committee of the entire project will be interviewed as well.

Result: The model "Raising Competencies through an Interdisciplinary and Cross-sectional Classroom for Staff in Dementia Care" will be presented as well results from the first interviews and observations will be presented.

Conclusion: Preliminary conclusions will be made at the presentation.



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Education and training of the workforce - Poster

P15-007

THE POWER OF COLLABORATION: ENGAGING AND EDUCATING YOUTH ON DEMENTIA THROUGH A UNIQUE SCHOOL-COMMUNITY-ACADEMIC PARTNERSHIP

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Abstract:

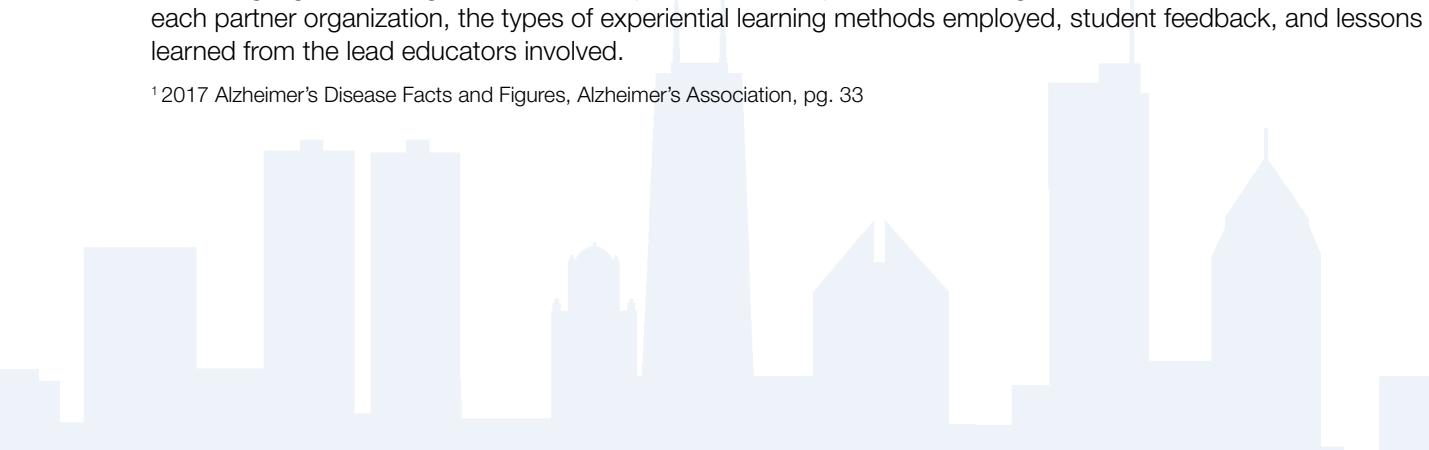
It is estimated that approximately 250,000 children and young adults in the U.S. between the ages of 8 and 18 help to care for someone with Alzheimer's or another dementia.¹ National surveys have found that approximately one quarter of dementia caregivers are in the "sandwich generation," meaning that they care for both an aging parent and for children under the age of 18.¹ These statistics indicate that children are impacted by dementia, and help to make the case for the importance of educating young people about Alzheimer's and other dementias, brain health, caregiver concerns, and the importance of a healthy lifestyle for maintaining brain health.

Clark Street Community School (CSCS) is a project-based public charter high school in the Middleton-Cross Plains Area School District in south central Wisconsin that uses an integrated curriculum and extensive community partnerships to enhance the learning of their students. In late 2014, CSCS became aware that the City of Middleton had recently been designated as a dementia-friendly community. At the same time, CSCS had begun forming partnerships with the Wisconsin Music & Memory Program, the Wisconsin Alzheimer's Institute (University of Wisconsin), and the State of Wisconsin Department of Health Services, to create an integrated curriculum for engaging and educating students regarding brain health, Alzheimer's and other dementias, dementia-related research, community programs for improving the lives of those impacted by dementia, and the vast array of potential career possibilities available to students interested in the dementia field.

The result has been four separate class offerings since 2015, beginning with a 3-week pilot, followed by two 18-week sessions, and currently a 9-week session. The course is titled "Music and Memory" and includes didactic material presented by the school's lead science and social studies educators, supplemented with an array of experiential learning opportunities made possible through community and academic partnerships with the Wisconsin Alzheimer's Institute, the Wisconsin Alzheimer's Disease Research Center, Music & Memory®, the Wisconsin Department of Health Services, the local library and senior center, area assisted living and long-term care facilities, and a number of additional content experts. Students take an active role in identifying specific areas of exploration and provide critical feedback regarding their learning.

This presentation will describe this unique and creative school-community-academic partnership approach to educating high school age students with specific attention paid to describing the overall curriculum, the roles of each partner organization, the types of experiential learning methods employed, student feedback, and lessons learned from the lead educators involved.

¹ 2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association, pg. 33





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Education and training of the workforce - Poster

P15-008

SUSTAINABILITY OF THE UNDERSTANDING DEMENTIA MOOC: PARTICIPANT MOTIVATION AND ENGAGEMENT

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Abstract:

Objective: The Understanding Dementia Massive Open On-line Course (UD MOOC) was made available for the first time in 2013. Designed to meet the broad dementia educational needs of both health workers and family carers, from 2014-2016 the UD MOOC was delivered as a free, 9 week, on-line course with 3 modules focussed on the brain, dementia pathophysiology, symptoms and care. From its inception, completion rates were considerably higher than that typically seen for an open on-line course. Other MOOCs have reported enrolment numbers falling on successive iterations and completion rates typically of less than 15%. Here we investigate the characteristics of the UD MOOC which underpin its sustainability.

Method: In order to determine the factors which influence its sustainability, participation data including enrolment, commencement, engagement, motivation and demographic attributes were examined and compared for 66,393 verifiable enrolments over 3 successive iterations from 2014-2016. Commencement was defined as completion of the first mini-quiz, engagement was defined as completion of sequential interim and end of unit quizzes, and motivation was determined through topic modelling analysis of discussion board posts and subsequent thematic analysis.

Result: Over three iterations, UD MOOC participants comprised a majority of females aged 44-60. 71% identified as family or paid carers of someone with dementia. Of those who enrolled, 44% commenced the course in 2014 rising to 58% in 2016. More than 75% of those commencing, remained engaged in the course to its conclusion in all three years. Patterns of engagement have remained consistent each year, with the most significant attrition occurring during Unit 1: The Brain. More than 96% of those who completed Unit 2: The Diseases also completed Unit 3: The Person. Themes emerging about motivation to complete were: relevance and applicability of content to work as a care worker or nurse; suitability of content to those caring for a family member with dementia; a recognition of the importance of dementia as a social issue; enjoyment of the learning process; acquisition of new skills and a commitment to completion.

Conclusion: Over successive iterations the UD MOOC remains atypical compared to other MOOCs, achieving consistently high completion rates amid a growing participant cohort with distinctive characteristics. Its success is underpinned by the broad relevance of its content to health care workers and family carers of people with dementia, the importance of dementia as a public health issue and an engaging and accessible model of information delivery.



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Education and training of the workforce - Poster

P15-009

THE INTERSECTION OF CULTURE IN THE UNDERSTANDING OF DEMENTIA AND PERSON-CENTRED CARE AMONG NURSING STUDENTS: A QUALITATIVE FOCUS GROUP STUDY

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Abstract:

Objective: The main objective was to understand the impact of student nurses' cultural heritage on their understanding of dementia and person-centred care to inform culturally sensitive and appropriate undergraduate education.

Methods: A qualitative exploration through focus groups was designed to elicit student nurses' perceptions of their cultural understandings of dementia and person-centred care. A question route was developed with key questions and prompts. Students were recruited from naturally occurring groups (pre-existing cohort), where existing relationships and social context support a deeper understanding of the topic (Githaiga 2014; Brown 2015). Focus groups provided a natural environment for a shared culture (Kitzinger 1994), so students were both influencing and being influenced by their peers, just as they would in the clinical or classroom setting. The focus groups were structured to allow a small number of students to share their cultural perceptions of dementia and person-centred care, but were also large enough to obtain a range of experiences (Krueger and Casey, 2009). All focus groups were audio recorded and transcribed verbatim. The Framework Method of data analysis as defined by Gale et al. (2013) was applied.

Results: Data were collected from two Higher Education Institutions in the South of England. Focus groups (n=10) were completed during November and December 2016, with first year (n=54) and third year (n=27) student nurses. Focus groups lasted between 24.21 to 52.21 minutes, with a mean average of exactly 40 minutes. Two overarching themes emerged from the analysis, cultural perceptions of dementia and a discourse regarding dementia and person-centred care. Cultural perceptions of dementia were framed by the students' experiences of growing up with family members with dementia, the importance of familial piety, the changing beliefs and understanding of dementia across generations, which was partially due to the impact of moving countries and continents. Students explored the language and discourse related to dementia lack of person-centred care through concepts such as; witchcraft, aggression, stigma, therapeutic lying and the need for raised awareness, especially in African countries.

Conclusion: Student nurses from diverse cultural background held different beliefs regarding dementia and person-centred care prior to commencement on an undergraduate nursing programme. All students discussed how their beliefs changed with the knowledge gained from both their lectures and clinical placements. During the study, all students were interested in understanding different cultural approaches to dementia and the care and support people with dementia received in different countries. Rather than being a taboo subject, students welcomed the opportunity to ask their colleagues about different cultural practices, and how these impacted on their friends and family. This study on cultural perceptions reinforces the need for open conversations in the classroom, to allow the exploration of different cultural heritages from the perspectives of student nurses. A facilitated discussion and reflection of cultural heritages will support the development of culturally aware healthcare professionals. In the UK, due to the diverse cultural population that exists, this needs to be embedded in dementia and undergraduate programmes and explored further in post-graduate curricula.



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Education and training of the workforce - Poster

P15-010

DEMENTIA AND SOCIAL INTERACTION: A SYSTEMATIC ANALYSIS OF COMMUNICATIVE BEHAVIOR OF PEOPLE LIVING WITH AD, SD AND BV-FTD.

Dr. Mandy Visser PhD*, Faculty of Health, University of Technology Sydney, Sydney, Australia; Deborah Parker Prof, Faculty of Health, University of Technology Sydney, Sydney, NSW, Australia and Fiona Kumfor PhD, Faculty of Science, University of Sydney, Sydney, Australia

Abstract:

Objective: This study investigates how dementia affects the way people socially engage while communicating with others. For people living with dementia, social interaction can be challenging. They regularly experience difficulties when expressing feelings and their behavior is often misread by others, affecting relationships and wellbeing. Earlier research shows indeed that people living with dementia experience several communication deficits in both their abilities to send and receive messages. However, different dementia syndromes progress in different ways; not all of these syndromes show early changes in the ability to connect and integrate (social) information or in emotional behavior. Therefore, this study examined changes in communication related to different dementia syndromes, by conducting a systematic analysis of spontaneous interactive behavior of people living with Alzheimer's disease (AD), semantic dementia (SD) and behavioral frontal temporal dementia (bv-FTD).

Method: For this, we video recorded 60 naturally occurring conversations between people living with dementia and an interviewer (a behavioral neurologist), preceding a series of neurological assessments. Conversations were non-scripted and lasted an average of ten minutes. All participants were living with younger onset (1 year post diagnosis) AD (20 participants), SD (20 participants) or bv-FTD (20 participants). Participants met diagnostic criteria for AD, SD or bv-FTD based on their neurological assessment, neuropsychological performance and MRI scan and were matched on age, sex, and cognitive level.

Observing the spontaneous behavior of our participants while interacting with the interviewer, we analyzed the presence of a variety of communication cues in the video recordings, namely 6 social engagement cues, 6 social disengagement cues and 6 emotional expressions.

Result: Preliminary results indicate a difference between people living with AD, SD, and bv-FTD for using social disengagement cues during the interviews, but no effect of dementia syndrome was found for using social engagement cues and expressing emotions. Social engagement cues were present for all dementia syndromes. Analyses showed an absence of use of emotional expressions, except for happiness, probably caused by the non-emotional nature of the conversations.

Conclusion: Overall, our preliminary results suggest that the dementia syndrome only affects the use of social disengagement cues (e.g., avoiding eye contact, self-grooming). However, this study merely focused on younger onset AD, SD and bv-FTD. A subsequent study (planned in May 2018) gives insight in how interactive behavior develops during the course of AD, SD, and bv-FTD, by including video analyses of communication cues in naturally occurring conversation with people living with AD, SD, and bv-FTD 3 year and 5 year post diagnosis. These studies are part of a research project that focuses on the development of communication protocols for people living with dementia, to be validated with Australian aged care organizations.



Education and training of the workforce - Poster

P15-011

ASSESSING THE IMPACT OF AN RMN SUPPORTING HEALTHCARE PROFESSIONALS IN DEMENTIA CARE IN ACUTE SETTINGS

Monika Rybacka^{*}, Dementia Care, University of the West of London, London, United Kingdom

Abstract:

Objective: People with dementia are more likely to experience unplanned admissions to hospital, which have negative consequences for them, and their carers (Dewing et al. 2016). Healthcare professionals' are best placed to address and change these outcomes, however poor knowledge and a lack of policies, guidance and resources impacts negatively on their attitudes and may result in a lack of person-centred and empathic care (Calnan et al. 2013; Jonas-Simpson et al. 2012)

Method: The implementation of a new role to support patients with dementia in the acute hospital setting: a registered mental health nurse as a Quality Improvement and Nurse Educator in Dementia. The role involved policy writing, pathway and local strategy planning, including the writing of the Trust Dementia Strategy, care plan development and formal and informal teaching on dementia.

Result: Quantitative results have been extracted from the completion of dementia education and training and cognitive screening. Dementia awareness was completed by staff, and increased from 11.7 % in 2014/15 to 93.38% in 2015/16. The dementia training knowledge package was completed by staff increased from 0.06% in 2014/15 to 77.71% in 2015/16. During 2014/15 the teaching was completed via an online e-learning tool, however in 2014/15 a taught classroom package was developed and the dementia awareness was also presented for new staff on Trust induction. Cognitive screening across the acute hospital increased by 22.44% to 67.51% from October 2015 until November 2016.

The role supported the growth and development of a dementia champion network, the developed previous initiatives further such as the Dementia Café and support staff within wards to design and implement projects to improve patient experience.

Conclusion: This fixed-term post demonstrated that a role specialising in dementia, such as the Quality Improvement Nurse Educator in Dementia could provide support, advice and teaching in an acute hospital setting, and thereby alongside other dementia initiatives improve the experience of staff, patients with dementia and their carers during an acute hospital stay.

The implementation of this unique role needs further exploration and evaluation, as current a consistency of training and specialist dementia roles restricts recommendations from a robust evidence-base (Brooke and Ojo 2017).





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P15-012

CREATIVE CONVERSATIONS: AN EXPLORATORY STUDY OF AN ARTS-IN-HEALTH APPROACH TO CARE STAFF DEVELOPMENT TO EMBED PERSON-CENTRED CARE AND IMPROVE COMMUNICATION BETWEEN CARE STAFF AND PEOPLE LIVING WITH DEMENTIA

Katherine Algar-Skaife^{*1}; Gill Windle¹; John Killick²; Luke Pickering-Jones³; Maria Caulfield¹; Jennifer Roberts¹ and Hannah Jelley¹, (1)Dementia Services Development Centre Wales, Bangor, United Kingdom, (2)Dementia Positive, Settle, United Kingdom, (3)Social Services, Flintshire County Council, Mold, United Kingdom

Abstract:

Introduction: Usual training for care home staff in the UK tends to focus on manual handling, fire safety, and safeguarding, rather than helping care staff understand how to communicate with older people, including those living with dementia (OPCW, 2014). However, previous research indicates that projects with artist practitioners engaging with people living with dementia in care homes also benefitted staff through learning new skills and increasing their understanding of the residents as individuals.

Objectives: This project aimed to develop and test a 'Creative Conversations' staff development intervention which used an arts-in-health approach to improve the quality of interaction between care staff and people living with dementia, and the knowledge and skills of the dementia care workforce. 'Creative Conversations' is based on and takes its inspiration from two earlier programmes: the Descartes project (Zeilig et al., 2015) and The Arts and Older People Project (Killick, 2015).

Methods: This exploratory study examined the feasibility and impact of the 'Creative Conversations' staff development intervention in a care home setting. Throughout the study, a collaborative approach ensured that those thought to benefit from the staff development programme (care staff, people living with dementia, older people, family carers and Social Services) were involved in the design and implementation. A pragmatic stepped-wedge cluster randomised trial explored whether there was a change in the quality of interaction between care staff and residents living with dementia, knowledge and skills, job satisfaction, and burnout of care staff, and social care-related quality of life of residents with dementia following the intervention. The exploratory nature of the study meant it was not powered to demonstrate effectiveness of the intervention but findings will inform a definitive trial.

Results: Nine care homes participated in the main study, with a total of 38 care home staff (mean age 42; 100% female) taking part. Preliminary qualitative findings suggest that 'Creative Conversations' enabled staff to gain a deeper understanding of resident personalities and needs as well as an enhanced awareness of their existing practices. Participants also appreciated the unique delivery and style of the sessions. This paper also presents preliminary qualitative findings from the trial. Along with these results, challenges and successes of the design of the project will be highlighted to enable the sharing of best-practice for evaluating complex interventions in care home settings.

Conclusion: An arts-in-health approach to care staff development offers an alternative to traditional training. Important implications have been learned regarding the feasibility of a stepped-wedge cluster randomised trial in care homes.

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Arts and Older People Project & Killick, J. (2015) The best words, in the best order. A toolkit for making poems in dementia care settings. Courtyard Theatre, Hereford, UK. <https://www.courtyard.org.uk/assets/CY-poetry-toolkit-small.pdf>

Zeilig, Poland, Killick & Fox, 2015, The arts in Dementia Care Education, *Journal of Public Mental Health* 14(1) 18-23.



POSTER ABSTRACTS

Education and training of the workforce - Poster

P15-013

ATLANTIC FELLOWS FOR EQUITY IN BRAIN HEALTH: A NOVEL APPROACH TO ADDRESSING THE INEQUITIES OF DEMENTIA THROUGH INTER-PROFESSIONAL LEADERSHIP TRAINING

Dr. Victor Valcour¹; Brian Lawlor²; Stacey Yamamoto³; Bruce Miller³ and Ian Robertson², (1)Neurology, Global Brain Health Institute, San Francisco, CA, (2)Global Brain Health Institute, Dublin, Ireland, (3)Global Brain Health Institute, San Francisco, CA

Abstract:

Established in 2015, the *Global Brain Health Institute (GBHI)* aims to reduce the impact of dementia around the world by training and supporting a new generation of leaders. In 2016, GBHI began training its first international and inter-professional cohort of **Atlantic Fellows for Equity in Brain Health**, hosted at two *Founding Sites*, Trinity College Dublin and University of California, San Francisco. Core hypotheses underlying our theory of change include:

- An integrated, inter-professional approach to brain protections strategies will allow novel, scalable and effective means to impact the burden of dementia.
- Approaches must address the needs of low and middle income regions, as most new cases of dementia will emerge from these regions.
- Creative social change will surface when these leaders are supported in a career-duration network.
- Approaches must address inequities, given that the greatest non-genetic risk factors for dementia are driven by the same social determinants that drive other physical illness and are deeply rooted in disparities.

We now report the first two years of program operation. Early indicators of success linked to these hypotheses include the diversity of profession and breadth of region of current and alumni *Atlantic Fellows*. To date, 52 individuals have been or are currently training at one of two *Founding Sites*. Twelve have been from the Mediterranean regions and 14 from Latin America, the two primary target regions for the first five years of operations. The diversity of profession includes clinicians (neurologists, geriatricians, internists), policy makers, economists, a lawyer, social scientists, journalists, and those in the arts (musicians, thespians, and an art director). Early indicators of impact are evidenced by Atlantic Fellow testimony:

"GBHI has changed my future. I [now] have broader knowledge and broader interests— My life will be different now... in the approach that I have in my field or the way I understand my research and the people I connect with." - current **Atlantic Fellow**

"I feel that more things are possible now that I have a network of support and mentoring. My GBHI experience gave me the confidence and support to get out of my comfort zone and try things I wanted but [was] afraid to try." – alumni **Atlantic Fellow**

Among early alumni, 9/9 returned to work in their home communities and of these, 7/9 resumed a position that they had prior to their Atlantic Fellowship experience. Two of nine started new positions with one *Atlantic Fellow* noting that her experience as an *Atlantic Fellow* contributed to the new employment.

These data support the ability to enroll and train emerging inter-professional leaders. Building a learning environment able to support such diverse trainees has been critical to our early success. Challenges include planning and implementing a common training curriculum that is relevant for *Atlantic Fellows* from diverse cultural, employment and regional backgrounds and refining individual trajectories of change given the broad cultural and political environments of each *Atlantic Fellow*. Through the **Atlantic Fellows for Equity in Brain Health** program, GBHI hopes to train 600 international Fellows in the next two decades.



POSTER ABSTRACTS

Education and training of the workforce - Poster

P15-014

UNDERGRADUATE STUDENTS DOING LIFE STORY WORK WITH PEOPLE WITH DEMENTIA: ENHANCING CARE WHILE LEARNING ABOUT THE CONDITION FROM A HOLISTIC PERSPECTIVE

Ms. Sumita M Strander*, Dartmouth College, Hanover, NH and Robert B Santulli, Psychological and Brain Sciences, Dartmouth College, Hanover, NH

Abstract:

Life Story Work involves reviewing events, attitudes, feelings, and states of mind from an individual's past and present life, with the goal of creating a personal, narrative history from the information gathered. Life Story Work has been shown to be highly valuable for people with dementia, helping them maintain a sense of identity and personhood in the face of a condition that gradually deprives the individual of critical elements of the self. In addition to aiding the person with dementia, Life Story Work helps spouses and other care partners better understand and feel closer to their loved one, and helps facility staff see the "whole person", rather than just the disease.

Life Story Work can also be a very useful method for teaching undergraduate students about dementia as a human process. Certainly, Life Story Work reveals the signs and symptoms of the illness, as well as its profound impact on the person and the family. However, the focus of the process is on the individual *behind* the illness - his or her life accomplishments, interests, talents, preserved abilities and the like. In this way, students come to understand dementia not just as a devastating condition, but also as a lived experience, in the context of the person's character, past and present life events, and relationships to family and society. Learning about dementia from individuals with the condition, rather than simply from textbooks and lectures, helps students appreciate dementia holistically. It helps improve student attitudes and preconceptions about the illness, and lessens the stigma surrounding it.

Living with Dementia is a ten – week experiential learning course offered to undergraduate students at Dartmouth College. In addition to traditional classroom didactics, pairs of students work closely with residents with dementia at a local continuing care retirement community. Students meet each week throughout the term with participating residents and their spouses, both separately and as a couple, and join them for meals or other activities at the facility. By the end of the term, students develop a detailed narrative of the life of the person with dementia, and give the written Life Story to the individual and his or her spouse. A copy of the Life Story is also given to facility staff. In addition, students write a detailed analysis of the process for the course.

This presentation will describe our program in detail, and discuss the effects of gathering and producing the Life Story on the students, the participating couples, and the staff of the facility.



POSTER ABSTRACTS

Education and training of the workforce - Poster

P15-015

IMPROVING DEMENTIA CARE IN GENERIC HEALTH SERVICE SETTINGS THROUGH STAFF TRAINING AND DEVELOPMENT IN THE UK

Sian Jones¹; Ellen Nelson¹ and **Piers M Kotting**², (1)UCL Partners, London, United Kingdom, (2)Medical School, University of Exeter, Exeter, United Kingdom

Abstract:

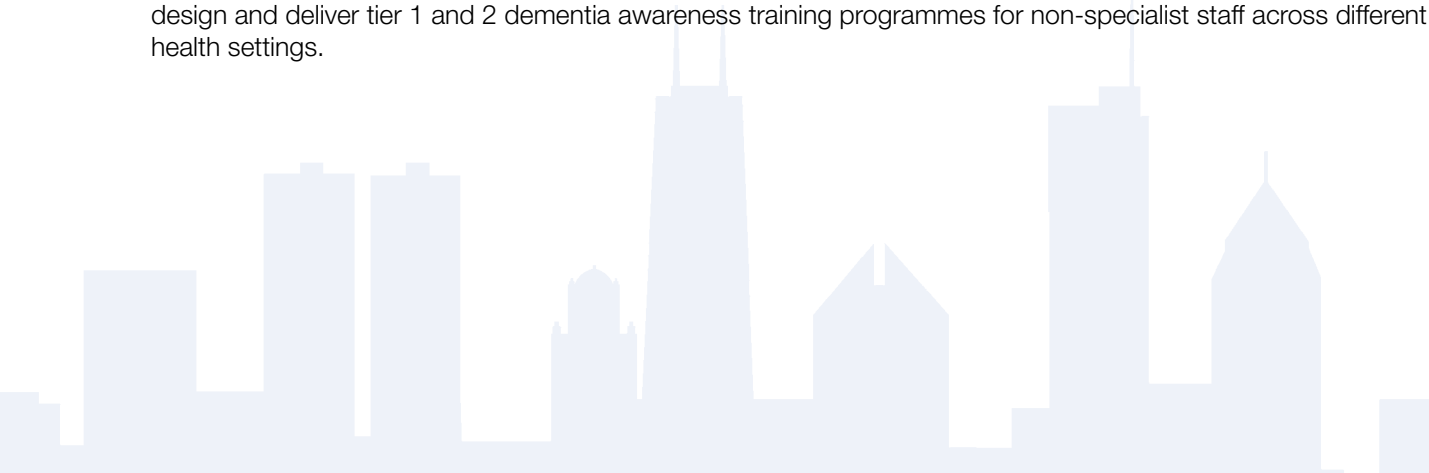
With the prevalence of dementia in people using generic NHS services increasing, and people with dementia shown to experience poorer outcomes, distress and confusion in these settings, it is increasingly important for staff across the care system to be sufficiently trained to ensure appropriate care for people with dementia.

UCLPartners, an Academic Health Science Network serving a 7m population across north, central and east London in the UK, has led a programme of work aimed at providing all staff working in clinical services across the network dementia training appropriate to their role, with the goal of improving dementia care across its services. Tier 1 and 2 training programmes have been developed, piloted and delivered to healthcare staff across 15 Acute NHS hospital Trusts, 12 Clinical Commissioning Groups and their General Practices, and 10 Community Education Provider networks.

The Tier 1 dementia training has been delivered to over 55,000 staff. The half-day simulation-based Tier 2 training has been delivered to over 6,000 staff across the network. A further Tier-2 training programme (CAPER training: Collateral, Assessment, Partnership, Enablement and Risk-positivity) was developed at the Royal Free Hospital NHS Foundation trust for ward staff, based on materials created by the UCLPartners project and delivered to 400 ward staff. Tier 3 advanced training is currently being delivered, creating Dementia Champions within Trusts, focused on specific Quality Improvement projects that will deliver improvements in dementia care locally.

95% attendees of core Tier 1 & 2 training reported an increase in confidence because of the training. 94% still use what they learnt in training in their current working practice, six months after receiving the training. 87% believe the care of people in their trust has improved since training began within their organisation. 97% attendees of the core Tier 2 training rate the course as excellent. 100% of staff attending CAPER training felt more confident to change the culture of dementia care on their ward, 6 months after training, compared with 20% pre-training. The Quality of Interactions Schedule (QUIS) tool was used to evaluate ward staff interaction with, and care of, dementia patients, with training participants observed pre- and 6 months post-training. 'Negative' interactions reduced from 33% to 2%, with 'positive' interactions increasing from 47% to 83%.

The training is now embedded within the core staff development programmes of participating organisations, with continuing commitment to improve the care for people with dementia and their careers. The key learning objectives for those attending this presentation are to understand the approach taken in London, and be able to design and deliver tier 1 and 2 dementia awareness training programmes for non-specialist staff across different health settings.





POSTER ABSTRACTS

Education and training of the workforce - Poster

P15-016

U-FIRST! TRAINING PROGRAM FOR PROFESSIONAL CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA

Ms. Cathy Conway, Alzheimer Society of Ontario, Toronto, ON, Canada

Abstract:

When we ask people who work with people living with dementia about the number one difficulty they face as a care provider, their answer is always a challenging behaviour, such as aggression, wandering, physical resistance or agitation. We call this behaviour “responsive,” because it is not unpredictable, meaningless aggression or agitation.

We understand that the person is responding to something negative, frustrating, or confusing in his or her environment; the reasons or triggers for challenging behaviours may be external rather than within the individual; and problems in the social or physical environment can be addressed and changed.

This presentation will show how U-First! training will help you and your staff to work more effectively with people living with dementia, creating a healthy workplace for all.

To date over 10,000 health care providers across Ontario and beyond have participated in U-First! training. It has been estimated that 90% work as Personal Support Workers. The overall vision is to provide every member of the care team with consistent hands-on training and key skills and best practices for providing care to a person presenting with responsive behaviours. This includes both dementia and other cognitive/mental illness. This focus on equipping and training staff (direct care providers) sets the stage for common knowledge, a common set of values, language for communicating across the system, and a common, comprehensive approach to care.

For staff caring for someone with dementia, the U-First! Program will help them:

- Understand that there can be many reasons why you might see behaviour changes when a person is living with dementia
- Flag the possible changes that you may see when you are supporting a person is living with dementia
- Interact in a new way with both skill and a common understanding of dementia
- Reflect and report on not only new behaviours you may see in the person you are supporting but also share your strategies, your tips on working with a person who is living with dementia
- Support the person with dementia, their family and friends in everyday activities
- Know that you are part of an important Team in caring for the person with dementia

This presentation will also show how our innovative education and training approach will help when staff are caring for people living with dementia. Through the course learners will meet the following Objectives: Explored and used the U-First!® Wheel (our collaborative tool) to discover changes and possible strategies for responding to a person with behaviour changes caused by dementia and/or other cognitive/mental illness.

1. Examined the importance of *understanding* all parts of the person and examined a case using the P.I.E.C.E.S.™ (Physical, Intellectual, Emotional, Capabilities, Environment, Social & Cultural) framework.
2. Reviewed the 7A's of dementia, identified examples of these and named how they could impact behaviour in a case. The 7A's include: Amnesia, Agnosia, Aphasia, Apraxia, Anosagnosia, Apathy and Altered Perception.



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3. *Flagged* behaviour changes in a case and identified the areas with the most risk/urgency.
4. Reflected on interactions with the person and other family or caregiving team members, how these effect behaviour, and decided on successful interactions using what we learn about the person.
5. Created ideas for supporting the person through a strong understanding of their strengths and needs.
6. Identified members of the team involved in supporting the person and named the valuable role that each can play.





POSTER ABSTRACTS

Education and training of the workforce - Poster

P15-017

DO YOU SEE ME: WHAT GOOD IS EDUCATION IF WE DON'T SEE THE PERSON BEHIND THE DISEASE?

Sharon Leitch Mrs* and Judith DeGroot, Faculty of Health, Kwantlen Polytechnic University, Surrey, Canada

Abstract:

Currently there are 564,00 Canadians living with dementia. Moreover, there are 25,000 new diagnosis of dementia in Canada every year ([AlzheimerCanada](http://AlzheimerCanada.ca)). We implore that amidst the portrayal of statistics to represent the growth of dementia in our societies, behind every number, there is a **PERSON** living with dementia. Members' of society who hope to support people living with dementia (PLWD) must see the person first and not the disease. Sadly, however, it has been our experience that resources available to provide knowledge and awareness of Alzheimer disease and other related dementia's priorities the disease over the person. The purpose of this presentation is to argue that, to provide support and care that are meaningful to the person living with dementia we must see "the **PERSON** before the disease" rather than the **DISEASE** before the person". To that end, we developed an Open Education Resource (OER) that consciously imbeds the PLWD in the first two modules; placing education of the disease in module three. www.dementiavoicelandchoice.com





Dementia policies and public policy initiatives - Poster

P16-001

THE KOREAN NATIONAL DEMENTIA HELPLINE; 4-YEAR EXPERIENCE

YunHye Jo¹; Seonjeong Byun² and Ki Woong Kim², (1)Strategic Business Dept., National Institute of Dementia, Seongnam, Korea, Republic of (South), (2)Department of Neuropsychiatry, Seoul National University Bundang Hospital, Seongnam, Korea, Republic of (South)

Abstract:

The National Dementia Helpline (NDHL) was established in November 2012 based on the Dementia Management Act (DeMA). As of December 2017, 22 full-time counselors are providing telephone counselling on 24/7 basis. The NDHL are taking about 400 to 700 calls per day. The number of calls has grown continuously; 2,213 in 2013, 17,763 in 2014, 54,989 in 2015, 78,933 in 2016 and 91,394 in 2017. The total number of calls reached about 250 thousands as of January 2018.

The NDHL provides Korean people with two types of counseling; 'Dementia Information Counseling' covered by 12 general counsellors and 'Dementia Care Counseling' covered by 10 professional counsellors. The former includes the information about signs, symptoms, causes, diagnostic procedures, prevention strategies, treatment options, and public services for dementia while the latter counsels about how to care dementia patients and how to relieve care burden and psychological distress. By the end of 2017, 87.6% (214,892 calls) was information counseling. The information counseling takes about 5 – 10 minutes per call on average. The care counseling usually takes more than 30 minutes per call. Actually overseas Koreans who are more fluent in Korean are also using the NDHL. The number of the NDHL is 1899-9988, meaning "Keep your memory of 18 until 99, Let's keep spry ('spry' sounds same as '88' in Korean) until 99".

The NDHL is also providing regional and local dementia centers with a call reception service during the centers close in the night-time of working days and holidays. The number of call receptions are also increasing; 145 in 2015, 238 in 2016, and 366 in 2017.

Finally the NDHL conduct nationwide telephone surveys on the users of NDHL to monitor their satisfaction with NDHL services and on the staffs of dementia centers and other dementia-related facilities to examine their unmet needs and performances.

Through these wide range of services, the NDHL acquired the Korean Industrial Standards (KS) in November 2017. We hope you will take the number of the NDHL with you and share it to the Korean seniors in your community.

Key words: Dementia, National Dementia Helpline, National Institute of Dementia, Dementia Counseling Centers





POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-002

ESTABLISHING THE PRACTICAL MODEL OF ADVANCE CARE PLANNING FOR PERSONS WITH DEMENTIA BASED ON THE IMPLEMENTATION OF PATIENT AUTONOMY ACT (POLICY) IN TAIWAN.

Yiling Yeh^{*1}; Dr. Chien-Liang Liu²; Sheng-Jean Huang¹; En Tzu Tien¹ and Mr. Shao-Fu Huang³, (1)Taipei City Hospital, Taipei, Taiwan, (2)Taipei City Hospital Heping Dementia Center, Taipei, Taiwan, (3)Academy of Humanities Innovation, Taipei City Hospital, Taipei, Taiwan

Abstract:

Persons with dementia are frequently denied the basic rights and autonomy available to others especially while the late stage of the disease. By the end of 2015, the Patient Autonomy Act was passed in Taiwan. This Act is stipulated to respect patient autonomy in healthcare and safeguard their rights to a good death through consultation of Advance Care Planning (ACP) provided by medical institutions, and the documentation of Advance Decision (AD). People with full civil capacity can sign AD to express whether they accept or reject to receive life-sustaining treatment (LST) when diagnosed with the specific clinical condition including severe dementia. The aim of this paper is to demonstrate what theoretical framework was applied to response the implementation of policy and how practice model was established at the program to provide advance care planning for people with dementia.

The multiple professional team was initially composed by a neurologist, nurse practitioners, medical social workers and psychologist. The model was developed by the amount of literature reviews and the analysis of the policy through expert meetings on a regular basis. At the beginning, the team designed the different levels of brochures based on the Trans-Theoretical Model (TTM) to help patients exploring the preferences about the choices of life-sustaining treatment while they meet the stage of severe dementia and educate the patients about the policy. Next, According to the act, the medical institution providing advance care planning may not affix its seal on the advance decision if there are sufficient facts showing that the person is mentally deficient. However, evaluating decision-making capacity were very challenging, especially among older adults with mild-to-moderate dementia. At the program, the guideline of assessing decision-making capacity had to be addressed and developed. Furthermore, according to the special needs of the population, a variety of decision aid tools are suggested to develop and apply in the process of Advance care planning.

A supportive and appropriate legislative environment based on internationally-accepted human rights standards is able to ensure the highest quality of service provision to people with dementia. Although the model of the Advance Care Planning program which was developed meet both requirements of the policy and special needs of persons with dementia. There are still clinical challenges which should be addressed in the future.



POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-003

SHIFTING THE RESEARCH PARADIGM TOWARD EFFECTIVE THERAPEUTIC DEVELOPMENT FOR ALZHEIMER'S DISEASE

Dr. Feng-Yen Li*, Research and Regulatory Affairs, Physicians Committee For Responsible Medicine, Washington, DC and Ann Lam, Green Neuroscience Laboratory, San Diego

Abstract:

Alzheimer's disease (AD) is the sixth leading cause of death, and its prevalence is expected to triple by 2050. Despite decades of research involving hundreds of experimental drug trials, there is no disease-modifying treatment available to date. One potential problem with the current research paradigm for AD drug discovery is its heavy reliance on animal experimentation for mechanistic research, toxicity testing, and proof-of-concept studies. However, animals do not naturally develop AD like humans do, and the many differences between humans and animals can lead scientists to therapeutic development failures filled with false hopes or potential loss opportunities. As such, although many drug candidates have seemingly cured AD in animals, none of them have succeeded in clinical trials. In addition to these false positive drug candidates coming from animal testing, the species-specific physiological differences between humans and animals may also lead to false negatives. This possibility is supported by the conflicting effects on cognition from a Mediterranean diet intervention in a mouse model of AD and in humans. The significantly greater percentage of drug candidates eliminated at the preclinical phase of drug development for AD relative to other diseases also indicates that using animals for preclinical drug development may falsely rule out potential drug candidates that would have succeeded in human drug trials. Yet, about 50% of current AD research funding is awarded to studies involving animals, and more efforts are being invested into developing new animal models for AD. As animals can never be made fully human and there will always be differences in molecular and structural wiring that can impede translation, we recommend two policies to shift the AD research paradigm to focus on producing human-relevant results: (1) allocating more research funding to studies developing or using human-predictive models or methods while reducing funding to studies on animals, (2) requiring demonstration of relevance of research findings in humans rather than animal models for grant applications and publications. The current drug development pipeline for AD can take more than a decade and several billion dollars to validate one drug candidate, but the success rate is only 0.5%. Supporting alternative human-relevant research tools and models to replace the use of animals for AD preclinical research—such as patient/epidemiological databases, patient tissue banks, xeno-free induced pluripotent stem cells and organoids, organ-on-chips, computational models, predictive toxicology frameworks such as adverse outcome pathways, etc.—may help increase the success rate and decrease the time and cost required for AD drug development. Moreover, such methods can be easier and less time-consuming to use for molecular mechanistic studies and toxicity assessments while also providing results that are more relevant and translatable to humans.





POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-004

TAKING VACANT SPACES IN SCHOOL FOR INDIVIDUAL WITH DEMENTIA AS CARE GIVING PLACE-AN EXAMPLE OF DAY-CARE CENTRE

Po-Tsung Chen^{*1};Lingyu Su²;Yating Wang² and Dinchan Shieh², (1)Institute of Gerontology, National Cheng Kung University, Tainan, Taiwan, (2)Herbert P.T. Architects & Associates, Tainan, Taiwan

Abstract:

Taking vacant spaces in school for individual with dementia as care-giving place has been a serious issue in Taiwan for years due to being an aged society. The purpose of this study aims to discuss the process of reviving vacant spaces in schools into day care centre for people with dementia.

Literature review, in-depth interview and focus group interview are conducted in this study. Interviewees include 15 government staffs and 6 from private conducting departments. The process of transition is discussed individually by dividing them into policy, preparation, planning and design stage in 5 focus group interviews.

The results indicate that whether vacant spaces in school could be transferred into a day-care centre for individuals with dementia successfully depends on : (1) supports from central authority and local government, (2) the initiatives by local government , and the following negotiations and propaganda, (3) positive attitudes from locals and education units, (4) friendly attitude toward neighborhoods, (5) the opportunities to interact with residents nearby so that people living with dementia could keep part of their own life, (6) adequate interaction opportunities between different cohorts, (7) the combination with local elements, (8) people's positive concepts toward dementia, (9) safety concern for children and people with dementia, (10) the independence while taking activities at the same time.

Base on the results, for those who want to run vacant spaces in school for people living with dementia into care-giving place, it is important to have the support from community and school members first, followed by the propagandas and intervention from the public sector that could make a friendly community for people with dementia.





P16-005

POTENTIALLY INAPPROPRIATE MEDICATIONS AND MEDICATION REVIEW AMONG PEOPLE WITH DEMENTIA IN ENGLAND: A RETROSPECTIVE COHORT STUDY USING THE CLINICAL PRACTICE RESEARCH DATALINK (CPRD).

Bryony Porter^{*1}; Antony Arthur¹; Kathryn Richardson¹; Duncan Edwards²; David Wright³; Nicholas Steel⁴ and George Savva¹, (1)School of Health Sciences, University of East Anglia, Norwich, United Kingdom, (2)University of Cambridge, Cambridge, United Kingdom, (3)School of Pharmacy, University of East Anglia, Norwich, United Kingdom, (4)Norwich Medical School, University of East Anglia, Norwich, United Kingdom

Abstract:

Objectives: People with dementia are often concurrently prescribed many different medicines for symptoms of dementia or other health conditions. Some medicines may be inappropriate if they have been used for too long or their potential harms outweigh their potential benefits. Potentially inappropriate medications can be defined using the Screening Tool for Older Persons Prescribing (STOPP) or Beer's Criteria. Limited research has focused on PIMs in people with dementia.

General Practitioners in England are expected to manage medications and are financially incentivised to provide comprehensive annual care reviews to all patients with a recorded dementia diagnosis. The impact of these reviews on medication burden is not known.

This study aims to estimate the prevalence of potentially inappropriate medication use and total medication burden, their association with dementia annual review or medication review and predictors of potentially inappropriate medication use among people with dementia in England between 2015 and 2017.

Methods: Data was extracted from the Clinical Practice Research Datalink (CPRD), one of the largest patient datasets in the world, comprising anonymised primary care patient data from ~7% of the UK population.

From CPRD we have extracted records of all prescribed medications, all medication reviews and annual care reviews for people with dementia between 1 Jan 2015 and 31 May 2017. The prevalence of prescription of four classes of potentially inappropriate medications (antipsychotics, tricyclic antidepressants, anticholinergics and proton pump inhibitors (PPI)) to people with dementia in primary care in England was estimated in each two-monthly windows across the study period.

Medications were defined using STOPP criteria. Antipsychotics, tricyclic antidepressants and anticholinergics were selected due to potential adverse effects in people with dementia and PPIs, which are commonly prescribed in older people, considered potentially inappropriate when prescribed for more than 8 weeks.

Results: 16,745 patients with dementia in England on 1 Jan 2015 were included. In each two-month time period, the median number of prescribed medications was 7 (IQR 6). 30.2% had a prescription of potentially inappropriate PPIs, 16.0% were prescribed anticholinergic medications, 8.2% were prescribed antipsychotic medications and 7.2% were prescribed tricyclic antidepressant medications. There were a total 11,553 recorded dementia annual reviews and 23,249 recorded medication reviews in England across the study period. We will present findings on the effects of medication reviews and dementia annual reviews and as well as patient and practice level covariates on the use of each potentially inappropriate medication.

Conclusions: The prevalence of potentially inappropriate medications and overall drug burden is an important marker of the quality of care for people with dementia. The findings will provide insight into the effectiveness of care reviews that are mandated or incentivised through national schemes, including Quality and Outcomes Framework (QOF). This work could improve guidance for practitioners conducting medication reviews for people living with dementia.



POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-006

US-INDIA ALZHEIMER'S FELLOWSHIP: EXPANDING THE ORGANIZATIONAL CAPACITY OF THE ALZHEIMER'S AND RELATED DISEASES SOCIETY OF INDIA

Mr. Nils Pieter de Mol van Otterloo*, USC Suzanne Dworak-Peck School of Social Work, 2051 La Fremontia St., South Pasadena, CA

Abstract:

The Alzheimer's and Related Disorders Society of India (ARDSI) is celebrating its Silver Jubilee in November 2018. Through the leadership of a number of individuals in ARDSI, Alzheimer's Disease International (ADI), and various connections in the United States there have been significant relationships developed over the course of nearly 20 years. Currently an effort is being undertaken to develop a fellowship that will serve to strengthen the foundation of resources at ARDSI in order to provide easier access to information related to dementia care in South Asia. South Asia has the fastest growing rate of dementia in the globe, and the least amount of money available for dementia care per capita. The US-India Alzheimer's Fellowship seeks to provide a model for linkage between philanthropic efforts, effective management, and research outcomes.





POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-007

DEMENTIA FRIENDLY COMMUNITY IN NEW TAIPEI CITY

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Abstract:

According to the prevalence of dementia in New Taipei City, the number of dementia patients is estimated to exceed 30000. Because of the misunderstanding about dementia in the community, caregivers shut the patient home and cause the disease to degenerate. Therefore, friendly community is particularly important for patients and caregivers. In addition, to raise public awareness of dementia and reduce stigmatization, it is necessary to cultivate acceptance of dementia and promote the quality of life for patients and caregivers.

Through the way of strengthening community action and knowledge, the awareness of dementia can be enhanced and also guided to thinking of practice a friendly community. To conduct discussion and analyze participant's activity satisfaction, the satisfaction rate with the activity more than 90%. The results showed the way upside down in the local community which can raise people's attention and participation in dementia and cultivate their own friendly service.





POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-010

HOW A DEMENTIA FRIENDS SESSION CHANGED ATTITUDES TOWARD DEMENTIA

Dr. Tricia L Cowan*, Nursing, Bemidji State University, Bemidji, MN

Abstract:

Objectives: Negative attitudes toward dementia can delay care and diagnosis, increase social isolation, and limit recognition of positive attributes of people living with dementia. The purpose of the study was to explore whether a Dementia Friends information session has an effect on attitudes toward people with dementia. **Methods:** One hundred-one community members and college students participated in a one-hour Dementia Friends information session. Participants were asked to complete the Dementia Attitudes Scale (DAS) immediately before and after the information session. **Results:** Eighty participants completed the DAS with a statistically significant positive change in scores from pre ($M = 110.7$) to post ($M = 121$, $p < 0.0001$). Both factors measured on the DAS, social comfort and dementia knowledge, showed statistically significant positive increase ($p < 0.0001$). **Conclusion:** These findings suggest that participation in a Dementia Friends information session can positively affect participants' attitudes toward dementia. This study was the first known to examine the effects of a Dementia Friends information session on attitudes toward dementia. As more communities implement Dementia Friends sessions, further research with larger and more diverse samples is needed.





POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-011

AN INTERGENERATIONAL TEACHING KITCHEN: REIMAGINING A SENIOR CENTER AS A SHARED SITE FOR MEDICAL STUDENTS AND ELDERS ENROLLED IN A CULINARY MEDICINE COURSE

Daniel R George^{*}, Humanities, Penn State College of Medicine, Hershey, PA and Tomi Dreibelbis, Office of Medical Education, Penn State College of Medicine, Hershey, PA

Abstract:

Objective: Culinary medicine has recently emerged as a curricular innovation to improve the capacity of medical trainees to provide nutritional information to at-risk patients. At Penn State College of Medicine, we sought to establish an intergenerational teaching kitchen within a senior center that paired fourth-year medical students with community-dwelling elders aged 70+ as participants in a Culinary Medicine course.

Method: We reached out to a local senior center located a half-mile from our medical school that offered free use of its kitchen and identified four elder volunteers willing to serve as “mentors” in an intergenerational Culinary Medicine course. During eight sessions held over two weeks, four medical students convened for three hours; in hour one, they learned advanced nutritional science behind disease states through case-based discussions geared towards chronic illness; in hour two, they were joined by elder mentors and worked collaboratively preparing recipes pertaining to the day’s lesson. This involved students and elders practicing basic cooking skills and informally discussing meal planning, shopping, and eating on a budget. In hour three, students and mentors taste-tested recipes and revisited nutritional concepts. At the course’s conclusion, students and elders submitted written reflections on the experience of working in an intergenerational shared site program.

Result: Our attempt to implement a model integrating elder mentors into an intergenerational Culinary Medicine course proved feasible. Partnering with a senior center was an effective strategy to gain access to a teaching kitchen as well as to elder volunteers who added an intergenerational dimension to classroom learning. In particular, mentors were grateful for the opportunity to share food-preparation techniques and offer personal stories (e.g. being affected by eating disorders) and guidance to students (e.g. be more aware of nutritional limitations faced by low-income patients) that helped ground nutritional science in a human context. Students expressed gratitude in having a chance to learn from elder volunteers and also identified moments where they were able to impart nutritional knowledge to elders and thus improve their clinical skills with geriatric populations. Both groups felt the small class size fostered close relationships and created solidarity.

Conclusion: Our pilot program established a model through which medical schools or other healthcare trainee programs can partner with senior centers to add a valuable intergenerational mentoring component to Culinary Medicine courses. Given the presumed co-occurrence of senior centers near medical schools in many cities, as well as the ease we found in forming such a partnership, it would be valuable for others to replicate and improve upon this model—perhaps engaging with residents of assisted living homes—as one facet of the larger project to help cities become more age- and dementia-friendly.

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Dementia policies and public policy initiatives - Poster

P16-015

AFTER THE DIAGNOSIS, WHAT? THE GREEK PARADIGM

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Abstract:

Today we are witnessing an unpreceded aging of our population worldwide. As a result, the impact of dementia is awesome. Persons, families and states have to face this existential, medical and socioeconomic challenge. In Greece there are 200.000 people with dementia and 400.000 caregivers looking after them.

Where do patients and families go to after dementia is diagnosed?
What is there for them?

Greek Alzheimer Associations have been active supporting people with dementia and their families and organising awareness campaigns for the public long. Until recently there was no Dementia Action Plan in place in Greece. Since earnestly pursued by all stakeholders for many years and after three years of hard work, a working committee presented a comprehensive Dementia Action Plan in March 2016. Consequently, the Greek Parliament approved it and enacted a law to ensure its implementation. This law, supported by the entire Greek political spectrum, authorised the establishment of an independent strategic public institution, the National Observatory for Dementia and Alzheimer's disease. It engages health professionals, other scientists, caregivers and members with specific expertise and provides guidance for organizing and promoting the national policy in dementia.

Current status regarding dementia in Greece is still inadequate. Services are fragmented and scattered. There are 21 Memory Clinics (NGOs, Medical Schools, NHS) and 9 Day Care Centers in Athens and Thessaloniki run by Alzheimer's Associations and financed by the State. Funding for research is limited but many research initiatives are running and there is active participation in international projects.

Compared to needs, services provided are woefully inadequate. Large areas of the country, especially rural and island areas are not covered by any services or facilities. The major problem is the lack of social care facilities, "Help at home" programs, respite care facilities and end of life centers throughout the country. Dementia is not recognized as disability and there are no tax allowances or financial benefits for people with dementia and caregivers. Legislative framework for dementia is missing. Stigma still surrounds Alzheimer Disease. Furthermore, the economic crisis makes things even worse.

Implementation of the National Action Plan has already started. So far:

- A national dementia registry is underway by the Greek National Health Organization.
- A rating system to measure the burden of dementia on families is being developed, taking into account severity of the disease, socioeconomic status, access to health and social care services. This will be used by the State to accordingly establish financial benefits for persons with dementia and their families.
- 6 Memory Clinics in the Psychiatric or Neurological Departments of General Hospitals in the Greek cities are organized
- 7 Dementia Day Care Centers in big cities and 9 Day Care Centers in collaboration with Municipalities in





POSTER ABSTRACTS

smaller cities are implemented throughout the country

- 3 hospices all over Greece are under construction

Major challenge is unquestionably financial! We have to balance the needs, set priorities and focus on targets that can be met currently. Our major goal is to build a broader base of engaged people, expand leadership at a national level and implement the plan in a collaborative way.

We aspire to reaching a point when the devastating effects dementia has on people and society will be globally and fully alleviated in Greece and all over the world.





POSTER ABSTRACTS

Dementia policies and public policy initiatives - Poster

P16-016

WOMEN AND DEMENTIA: A GLOBAL CHALLENGE

Amy Little, Global Alzheimer's & Dementia Action Alliance (GADAA), London, United Kingdom and **Kate Swaffer Ms***, Dementia Alliance International, Adelaide, Australia

Abstract:

This presentation will reflect the Global Alzheimer & Dementia Action Alliance's work on the issue of women & dementia, showcasing a 4 minute short film '[And Then I Looked Up Dementia - Women Speak Out](#)', and exploring why dementia is a global women's health, social care and rights issue that can no longer be ignored.

"I'm here today to speak about the women left behind because of ignorance, because of prejudice, because they are simply dealt a card in life that gave them a medical condition: dementia." In November 2017 the actress Carey Mulligan addressed the UN Secretary General and delegates at UN Headquarters in New York to call on governments and international civil society to unite for a world where no woman is left behind because of her dementia.

While there is growing recognition of the scale of the global dementia challenge, there is a key issue that continues to be significantly overlooked. Women are disproportionately affected by dementia.

More women than men live with the condition, they provide the majority of care support and they face the greatest stigma.

Two thirds of dementia care partners worldwide are female, rising to more than 70% in lower and middle income countries. Those who support people living with the condition often have to make changes to their employment situation and women are more likely than men to reduce their hours to part-time, or stop work completely, to provide support to those living with dementia.

The stigma surrounding dementia exists universally and extreme forms of discrimination can lead to abuse. Older women affected by conditions such as dementia are exposed to what has been termed a 'triple jeopardy' discriminated against as a result of their age, sex and condition.

Dementia is listed by the World Health Organisation in the top five causes of death for women worldwide and it is now the biggest cause of death for women in countries such as the UK and Australia, yet currently only twelve countries offer gender-sensitive responses to the condition.

In this session we will share a global perspective on what individual, local, national and global actions can be taken towards ensuring a gendered approach to dementia. We are calling for (1) Governments, international civil society and partners to get behind this global challenge and unite for a world where no woman is left behind because of her dementia. (2) A gender-perspective to be included in all dementia policies and plans, with sufficient resource allocation to ensure their implementation. (3) Further research to understand the impact of sex on dementia and to find gender-sensitive approaches for better diagnosis, treatment, care and awareness of dementia.



P17-001

INVESTIGATION OF PHYSICAL FITNESS PERFORMANCE FROM A PREVENTIVE VIEW IN COMMUNITY-DWELLING ELDERLY WITH MILD TO MODERATE DEMENTIA

Ms. Yi-Chun Chein¹; Ms. Jui-Chi Hsu¹; Jung-Cheng Yang¹; Yi-Chen Tsai¹; Yu-Ying Chu²; Meng-Ru Tsai¹; Yi-Hui Lu¹ and Wun-Hung Chen¹, (1)Phys Med & Rehabil, National Taiwan University Hospital Hsin-Chu Branch, Hsin-Chu, Taiwan, (2) Nursing Department, National Taiwan University Hospital Hsin-Chu Branch, Hsin-Chu, Taiwan

Abstract:

Background: Physical fitness is an important factor for an individual to live a functional lifestyle, since many functional movements depend on having sufficient muscle strength, endurance, flexibility, and balance. Identifying the area of decline in physical fitness and providing appropriate intervention is critical when wanting to maintain or even improve the quality of life of people with mild or moderate dementia.

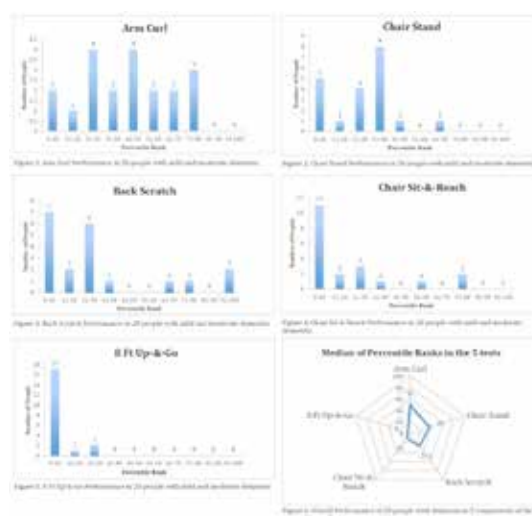
Objective: The goal of this study was to investigate the physical fitness of community-dwelling elders with mild or moderate dementia and compare their performance to healthy elders.

Method: Men and women aged 65 and older diagnosed with mild or moderate dementia were recruited from a community in Taiwan. Participants could walk independently and lived at home. Physical fitness was evaluated by physical therapists using 5 components from the Senior Fitness Test, including the Chair Stand, Arm Curl, Chair Sit-&Reach, Back Scratch, 8-Ft Up-&Go. Then the data was compared with a normative containing the scores of healthy elders, according to their age range. This normative was established by the Public Health Bureau of Chiayi City in 2013. The comparison was to see at what percentage rank the individual's fitness status was when compared to healthy elders of the same age range.

Result: 20 community-dwelling elders (6 men and 14 women, mean of age 81.75 years old) diagnosed with dementia participated in this study. The study group's performance in the Arm Curl was similar to healthy elders (Figure 1). For the Chair Stand and Back Scratch, most of the people were below 40% of the elders in their same age range (Figures 2 and 3). As for the Chair Sit-&Reach and 8 Ft Up-&-Go test, most of the people performed lower than 10% of the same age range population (Figures 4 and 5). Looking at the overall performance of the study group (the median of each individual's percentage rank in the same test), their upper limb strength percentile rank was closer to 50% of the healthy individuals, while their lower limb strength, upper and lower limb flexibility were only at the 35%, 27.5% and 10% percentile rank. In the test for dynamic balance, the study group had a percentile rank of 5% (Figure 6).

Discussion: The lower limb strength, flexibility of the upper and lower limb of these elders were not as good as healthy elders in the same age range. A decrease in lower limb strength and flexibility might lead to a difficulty in walking, climbing stairs or obstacle crossing. The dynamic balance ability of these people was only at a percentile rank of 5%, which show that they are more vulnerable to fall down.

Conclusion: Given the above findings, exercise targeted to maintain or improve the lower limb strength, the flexibility, and dynamic balance of people with mild and moderate dementia should be emphasized to prevent functional decline and help them live a healthy lifestyle.





POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-002

SYNERGISTIC EFFECTS OF AB AND A-SYNUCLEIN NEUROTOXICITY ON IMPAIRMENT OF INSULIN SIGNALLING IN DEMENTIA WITH LEWY BODIES (DLB)

Te-Jen Lai¹; Jia-Ling Hsieh²; Hsin-Hua Li²; Yen-Ting Chang² and Chih-Li Lin², (1)Department of Psychiatry, Chung Shan Medical University Hospital, Taichung, Taiwan, (2)Institute of Medicine, Chung Shan Medical University, Taichung, Taiwan

Abstract:

Objective: α -Synuclein has been indicated as a primary cause for the formation of Lewy bodies, particularly in the pathogenesis of dementia with Lewy bodies (DLB). Although the initial steps of the α -Synuclein-associated neurotoxicity in DLB remain unknown, some studies demonstrated that many DLB cases often simultaneously display amyloid β (A β) depositions in the brain. However, the possible molecular mechanisms of A β contributes to α -synuclein-induced neurotoxicity remains unclear.

Method: To investigate molecular pathways involved in A β -mediated α -Synuclein pathology, we established both in vitro and in vivo models for α -Synuclein overexpression cell lines and rats.

Result: Our results demonstrated that co-treatment with A β in α -Synuclein-overexpressed conditions significantly increases α -Synuclein intracellular aggregation and neurotoxicity. Moreover, A β also caused AMP-activated protein kinase (AMPK) inhibition and impaired insulin sensitivity, which leads to significant oxidative stress in enhancing α -Synuclein toxicity.

Conclusion: Our findings indicated that neuronal insulin resistance could be one of the causative factors of α -Synuclein toxicity, and the strategies for insulin sensitization may have therapeutic potential for synucleinopathies including DLB.





POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-003

LATE LIFE DEPRESSION AND COGNITIVE DECLINE

Lina M Velilla*, Global Health Brain Institute, Medellín, Colombia

Abstract:

Objectives:

Aim I: To analyze the cognitive differences between individuals with depression symptoms late in life and individuals with no depressive symptoms.

Aim II: To analyze longitudinally the cognitive changes in individuals with depressive symptoms late in life compared with individuals with no depressive symptoms.

Method: Retrospective analysis of a cohort with 295 individuals with depressive symptoms late in life and with neither MCI nor dementia at the baseline. The subjects were classified as no depressive symptoms, mild depression and severe depression according the GDS long version scores. The cognitive status was classified according the CDR. All the subjects underwent a neurological and cognitive follow up.

Result: After adjusting for potential cofounders such as gender, age and education the group with depressive symptoms performed significantly worse ($p < 0.05$) on the MMSE, verbal and visual memory, executive function and visuospatial tests. We found similar results when we comparing across the three levels of depression. After performing a lineal multilinear model we observed a higher cognitive decline among the subjects with more severe depressive symptoms over the subjects with no depressive symptoms.

Conclusion: Despite evidence links late life depression and Alzheimer Disease (AD) with enough independence between cognitive decline associated with a depressive illness and the decline encountered in Alzheimer's disease, it is remained a diagnostic gap in outpatients clinical settings to distinguish between late life depression and prodromal Alzheimer's disease because the clinical frame of both conditions is quite similar. The cognitive follow up is a useful and inexpensive tool to underline the cases of progressive cognitive decline related with AD at the primary and secondary clinical settings. It is important to grow the body of knowledge regarding depression late in life, its relationship with cognition among elders and its role as a potential modifiable risk factor for dementia.





POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-004

THE SEEDS PLAN: APPLYING PRINCIPLES OF EVOLUTIONARY MEDICINE TO NATURALLY PREVENT ALZHEIMER'S DISEASE

Jennie Ann Freiman MD*, Author, The SEEDS Plan, Santa Fe, NM

Abstract:

Given the global epidemic showing no signs of slowing, and approved treatments uniformly incapable of modifying the underlying disease, Alzheimer's prevention is an urgent public health priority warranting innovative stratagems. SEEDS is a multifaceted, evolution-based, comprehensive lifestyle plan that can be individualized to prevent, slow, and if in its early stages, reverse Alzheimer's disease. The five actionable pillars of prevention include strategies for S(leep), E(at), E(xercise), D(omain), and S(ocial).

Evolutionary medicine, a systems biology approach to managing processes that promote disease vulnerability, shifts the conventional focus from health stabilization to aggressive promotion of resilience and robust adaptation to modern conditions. Human biology and behavior are genetically adapted to the specific evolutionary niche that was the historically normal environment for millions of years of human evolution. Antagonistic pleiotropy, the concept that genes beneficial in one setting may be detrimental in another, underlies the Darwinian explanation of Alzheimer's disease. Alzheimer's is a modern lifestyle disease arising from the mismatch between slowly paced genetic adaptation and rapid changes in lifestyle and environment that accelerated post-industrialization. Evolution selected for longevity and healthy brain aging by co-partnering productive hippocampal neurogenesis with neuronal rejuvenation, two natural processes that maintain brain plasticity to the highest age. Applying Darwinian theory to health and disease is an alternative perspective that can generate practical risk reduction and disease management measures.

The recent Lancet Commission on Dementia Prevention reported that at least one third of global dementia cases can be prevented by lifestyle modification. The SEEDS Plan incorporates these and other evidence-based and epidemiologic strategies to make Alzheimer's a distant memory.





POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-006

WHITE MATTER HYPERINTENSITIES ARE ASSOCIATED WITH FALLS IN OLDER PEOPLE WITH DEMENTIA

Morag E Taylor^{*1,2,3}; Stephen R Lord^{1,4}; Kim Delbaere^{1,4}; Wei Wen^{5,6}; Jiyang Jiang^{5,6}; Henry Brodaty^{6,7}; Susan Kurrle³; A Stefanie Mikolaizak⁸ and Jacqueline CT Close^{1,2}, (1)Falls, Balance and Injury Research Centre, Neuroscience Research Australia, Sydney, Australia, (2)Prince of Wales Clinical School, Medicine, University of New South Wales, Sydney, Australia, (3)Cognitive Decline Partnership Centre, Sydney Medical School, The University of Sydney, Sydney, Australia, (4)School of Public Health and Community Medicine, University of New South Wales, Sydney, Australia, (5)Neuropsychiatric Institute, Prince of Wales Hospital, Sydney, Australia, (6)Centre for Healthy Brain Ageing, School of Psychiatry, Medicine, University of New South Wales, Sydney, Australia, (7)Dementia Centre for Research Collaboration, School of Psychiatry, Medicine, University of New South Wales, Sydney, Australia, (8)Department of Clinical Gerontology, Robert-Bosch-Hospital, Stuttgart, Germany

Abstract:

Objectives: White Matter Hyperintensities (WMHs) are associated with impaired gait, balance and cognition, as well as falls, in cognitively healthy older people. However, there remains a paucity of literature examining these relationships in older people with dementia. Understanding WMHs mechanistic role in falls may assist in developing effective fall prevention strategies. Therefore, we investigated the relationship between baseline WMHs and baseline cognitive and physical function, and prospective falls in older people with dementia.

Methods: Twenty-eight community-dwelling older people with mild-moderate dementia underwent magnetic resonance imaging and assessment of physical (Physiological Profile Assessment) and cognitive (global and processing speed) function at baseline. WMHs (total, periventricular and deep) were quantified using a fully automated segmentation toolbox, UBO Detector (<https://cheba.unsw.edu.au/group/neuroimaging-pipeline>). Falls were ascertained prospectively using monthly calendars and telephone calls for 12-months with the assistance of carers.

Results: The median age of the participants was 83 years (IQR 77-86) and 36% were female. In cross-sectional analyses, total WMHs were significantly associated with poorer global cognitive and physical function. In longitudinal analyses, total, periventricular and deep WMHs were significantly associated with faller status (0 vs 1+). These relationships withstood adjustment for age, sex, intracranial volume and vascular risk. Each standard deviation increase in total WMH volume resulted in a 33% increased risk of falling.

Conclusions: WMHs were associated with poorer physical and global cognitive function in older adults with dementia. In adjusted models, total, periventricular and deep WMHs were associated with falls. Further research is needed to confirm these preliminary findings and determine whether management of vascular risk, and therefore development of WMHs, can reduce falls and improve cognitive and physical function in people with dementia.



POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-007

GLOBAL COUNCIL ON BRAIN HEALTH: RECOMMENDATIONS FOR PROMOTING BRAIN WELLNESS AND HEALTHY AGING

Sarah Lock^{*}, Policy, Research & International, AARP, Washington, DC, DC and Ms. Lindsay R Chura, Global Council on Brain Health, AARP, Washington, DC

Abstract:

Our global society is undergoing an unprecedented demographic shift with the aging population now comprising the fastest growing demographic. As people live longer, the need for clear, trustworthy information on brain health based on the most up-to-date neuroscience findings is greater than ever. The Global Council on Brain Health (GCBH) was launched by AARP, in collaboration with Age UK, and aims to provide the scientific foundation for policy recommendations to improve public health. The Council is an independent collaborative of scientists, physicians, scholars and policy experts convened to provide the foremost thinking on what people and professionals can do to maintain and improve brain health. A core group of thirteen experts from around the world comprise “the hub” or governance committee. This group leads issue-matter experts – “the spokes” - in examining lifestyle priority areas. Surveys have been conducted to ascertain ways in which AARP can engage with the public to promote brain health and provide information on topics of most interest. The Council has released consensus reports on the following topics: physical activity, sleep, social engagement, cognitively stimulating activities and nutrition. These reports focus on risk reduction as a way of promoting and maintaining brain health. To this end, the GCBH strives to translate scientific findings into actionable steps that can be achieved through innovative strategies. This presentation will provide a framework to discuss the issues of greatest importance to people and their clinicians.





POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-008

EVALUATION OF A MEMORY WELLNESS CLINIC

Christine Stirling¹; Helga Merl²; Ashley Turner³; Indra Arunachalam⁴ and Carolyn King Dr³, (1)School of Health Sciences, University of Tasmania, Hobart, TAS, Australia, (2)IntegratedLiving, Sydney, Australia, (3)University of Tasmania, Hobart, Australia, (4)Integrated Living Australia, Sydney, Australia

Abstract:

Objective: This study evaluated the effectiveness of a community based 'memory wellness' program. The program aims to help older people change behaviours to decrease their dementia risk factors.

Lifestyle risk factors such as poor nutrition, smoking, and alcohol overuse, as well as management of chronic conditions such as high or low blood pressure, blood glucose and cholesterol levels are known dementia risk factors. The focus of interventions to delay the onset of dementia symptoms or to prevent long term conditions such as dementia, include lifestyle modifications to reduce risk factors, increased health knowledge and health promoting behaviours.^[1-3]

Method: This mixed methods evaluation collected pre and post clinical data using a broad and deep sampling strategy on an NGO run community health program. Clinical information about BP, Weight, BMI BGL, ACE-III, and DASS scores were collected from groups across thirteen locations in three states of Australia. Additional data was collected using scales for social isolation, technology use and stages of change data across four sites in the Australian state of Tasmania. One hundred and seventy-nine participants were recruited into the study over a two year period, with nine withdrawals. Participants received health screening before and after the program; an eight week group training program using iPads that focused on addressing risk factors for dementia, and a further 1 month of self-directed goal focused activity using the iPad. Post data collection was carried out three months after commencing the program. There was a significant amount of missing pair data ranging from 30 on the ACE-III to 100 for the DASS scales. Paired *t*-tests were carried out on all clinical data. Interviews with 15 participants were carried out approximately 4 weeks after the program finished.

Result: There were no changes between participant's pre and post weight, BMI, BGL or blood pressure, but there were statistically significant changes in ACE-III (*t* 3.42, ES 2.63 [medium] *p* > .001), DASS -Anxiety (*t* - 2.4, ES 0.752 [large], *p* > .05) and DASS - Stress (*t* -2.61, ES 0.851 [large] *p* > .05) scores. Overall interviewees were happy with the program in particular working in a group and peer support.

Conclusion: This community based program evaluation demonstrated increases in cognitive function, and decreases in anxiety and stress over a three month program. While the evaluation lacked a control group, the medium to large effect sizes and statistically significant results suggest that further research is warranted in how well community programs can improve memory and mental health in the older population.

1 Hopper, T., et al., *An Evidence-Based Systematic Review on Cognitive Interventions for Individuals With Dementia*. American Journal of Speech-Language Pathology, 2013. **22**(1): p. 126-145 20p.

2 McLaren, A.N., M.A. LaMantia, and C.M. Callahan, *Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia*. Aging & Mental Health, 2013. **17**(6): p. 655-666 12p.

3 Ngandu, T., et al., *Articles: A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial*. The Lancet, 2015. **385**: p. 2255-2263.



POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-009

PREVENTING DEMENTIA THROUGH BUILDING COMMUNITY KNOWLEDGE AND CAPACITY: THE REACH AND IMPACT OF A MASSIVE OPEN ONLINE COURSE

Maree Farrow¹; Shannon Z Klekociuk¹ and James Vickers², (1)Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, Australia, (2)Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, TAS, Australia

Abstract:

In the absence of disease modifying treatments, addressing modifiable risk factors presents an opportunity to curb the growing numbers of people expected to be affected by dementia. Population-based estimates suggest around one-third of cases are potentially preventable. Even modest reductions in the incidence of risk factors are estimated to prevent millions of cases and save billions of dollars globally. Despite this, public knowledge of dementia risk factors and the potential for risk reduction remains low.

The Preventing Dementia Massive Open Online Course (PD MOOC) was developed by the Wicking Dementia Research and Education Centre, University of Tasmania, to provide free and accessible education on current evidence for dementia prevention. The course aims to meet the need for accurate evidence-based information to be available to those concerned about their dementia risk, such as those with a family history of dementia, and to relevant service providers, through building community-wide knowledge and capacity to tackle modifiable risk factors, potentially leading to reduced prevalence of dementia.

Across 5 weeks, the PD MOOC explored modifiable risk factors for dementia related to lifestyle, vascular health and cognitive reserve. The course also discussed dementia as a global public health issue, the non-modifiable risk factors of age and genetics, myths about dementia risk and causes, barriers and enablers of health-behaviour change, and ongoing initiatives in dementia prevention research. Information was presented in five modules, using interviews with international experts, animated video material, infographics, and interactive discussion boards. Participants provided demographic information at enrolment and completion of the PD MOOC was defined as a passing grade of 70% on 3 quizzes.

The first two offerings of the PD MOOC in 2016 and 2017 attracted 11,185 and 15,620 international enrolments respectively. Of these, 49% completed the 2016 PD MOOC and 53% completed the 2017 course, the highest completion rate for any English language MOOC. Across both courses, 88% of participants were female, their mean age was 48 years, 62% were university educated, and 70% were Australian. While the 2016 PD MOOC attracted many who had previously undertaken the Wicking Centre's Understanding Dementia MOOC and were working in dementia care, the 2017 course attracted fewer professional dementia carers (61% vs 75%) and more participants with a family history of dementia (46% vs 39%). This suggests increasing participation by the PD MOOC's target audience – middle-aged adults who can benefit most from lifestyle modifications to reduce dementia risk.

Participant feedback suggests many are motivated to apply what they have learned to making lifestyle changes to reduce their risk. The impact of the PD MOOC will be further measured by the capacity of this educational offering to influence changes in behaviours related to dementia risk. Our research program will also investigate whether positive behaviour change can be sustained and what additional support people at risk of dementia may need. This program may also lead to a range of new initiatives and partnerships with organisations who are likewise interested in reducing dementia risk in the population.

We aim to establish the PD MOOC as an effective public health intervention, building health literacy related to modifiable risk factors for dementia to inform changes in risk-related behaviours.



Prevention (risk reduction and risk factors) - Poster

P17-010

IN FORMA MENTIS: A MULTIMODAL PROJECT TO PREVENT COGNITIVE DECLINE

Andrea Fabbo^{*}, Local Agency for Health of Modena, Modena, Italy; Petra Bevilacqua, ASDAM Association Mirandola, Mirandola, Italy; Daniela Tagliaferri, Opera Pia Castiglioni Formigine, Formigine- Modena, Italy and Lucia Bergamini, Cognitive Disorders and Dementia Unit, Local Agency for Health of Modena, Mirandola, Italy

Abstract:

Objective: Italian country is experiencing the aging of population and increased longevity, and the incidence of dementia is expected to raise. Interventions for risk factors such as more childhood education, exercise, maintaining social engagement, reducing smoking and management of hearing loss, depression, diabetes, obesity and treatment of hypertension in middle aged and older people might have the potential to delay or prevent one third of dementia cases. One of these interventions is the regular participation to physical activity or mental exercises. There is controversial evidence that connects regular physical activity or exercise to higher cognitive function, decrease cognitive decline and reduced risk of Alzheimer's disease or Dementia. The In-Forma Mentis Project represents an attempt to integrate two psychosocial interventions to stimulate both cognitive functions and physical abilities.

Method: the project envisages a psycho-educational course of 8 meetings of 2 hours each conducted by a psychologist and a physiotherapist. At each meeting a memory-related topic will be treated and both cognitive and physical exercises will be performed. Between one meeting and the other participants are provided by intensive memory exercises and training to be done at home. The pilot project provided for model testing for a group of 33 people, aged 63-88, without cognitive decline. The meetings are planned to last 2 months and at the beginning and at the end of the cycle an assessment of cognitive evaluation, functional and emotional, composed by ACE-R, MMSE, GDS-15, MAC-Q, SPPB, will be submitted to the participants (26 cases: 10 M, 18 F, average age: 78,73; average years of schooling: 12,65).

Result: we observed a statistically significant improvement in cognitive functions pre- and post-intervention measured with ACE-R ($t=-6,711$, $p 0,000^*$) and MMSE ($t=-3,934$, $p 0,001^*$), an improvement (not statistically significant) in mood (measured with GDS-short 15 items, $t=2,034$, $p 0,053$) and an improvement in subjective memory disorders measured with MAC-Q ($t=8,964$, $p 0,000^*$). We did not observe significant improvement in the SPPB test, an established tool used to assess the physical performance of elderly's lower extremity and a prognostic indicator for disability and hospital admission ($t=0,625$, $p 0,538$).

Conclusion: the results are very promising and future research can facilitate the spread of this project and further observations to current status. During 2018-2019 new courses will be arranged in various dwelling community of Modena (Italy) according to the protocol of pilot project.



POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-011

DISRUPTING DEMENTIA: MITIGATING THE WORLD'S LARGEST IMPENDING HEALTHCARE PROBLEM VIA COGNITIVE EXERCISE

Dr. John DenBoer SMAR[®], Neuropsychology, SMART Brain Aging, Inc., Scottsdale, AZ

Abstract:

Objective: The combined effects of the aging of the population (caused by the shift of the baby boomer generation into dementia) and significant increase in life expectancy has combined to put dementia into the range of our largest medical, if not societal, problems. In the state of Arizona, there is a projected 44-72% increase in dementia.

Research has supported the use of cognitive intervention exercises to reduce early-stage dementia. Valenzuela and Sachdev (2009), in a literature review of 22 studies (involving approximately almost 30,000 individuals), found an overall risk reduction of 46% in individuals that were found to engage in a high level of regular cognitive activity. Perhaps more importantly, they found a dose-dependent relationship between cognitive exercise and reduction of dementia, which had not been found previously.

Method: The SMART Memory Program (DenBoer, 2008) is a cognitive intervention designed to promote the reduction of early-stage dementia. Results of this program have shown significant promise (e.g., DenBoer, 2013), and the present researchers are currently engaging in multiple research studies. The program is effective via the use of new and novel cognitive exercises.

Result: The researchers present research results gathered from multiple randomized clinical trial's (RCT's), which is considered the gold-standard of research in this area. This presentation focuses on the results of a joint study with UCLA in which the researchers examined the effects of the SMART Brain U Online program on individuals with amnesic MCI (aMCI).

Conclusion: There is promising research in the area of dementia prevention and awareness, although more RCT's are certainly needed.





POSTER ABSTRACTS

Prevention (risk reduction and risk factors) - Poster

P17-012

INNOVATIVE STRATEGIES COMBINING EXERCISE MODIFICATION AND THE MEDITERRANEAN DIETS TO REDUCE THE RISK OF DEMENTIA

Zhong-Han Lee¹; Hui-Ya Lin¹; Chun-Chun Chen¹; **Dr. Chien-Liang Liu²** and Shiou-Sheng Chen², (1)Zhongzheng District Health Center, Taipei, Taiwan, (2)Taipei City Hospital Heping Fuyou Branch, Taipei, Taiwan

Abstract:

Objective: Growing evidence suggests the relationship between dementia and noncommunicable diseases. According to the *Global action plan on the public health response to dementia 2017-2025* issued by WHO, diabetes is one of the risk factors of dementia. Physical inactivity and unbalanced diets are lifestyle-related risk factors for diabetes as well as several noncommunicable diseases. We tried to promote physical activity and healthy and balanced diets for prevention of diabetes and dementia.

Prevention of Dementia By Lowering the Prevalence of Diabetes with Health Promotion



Promoting healthy and balanced diets



Promoting physical activity

Training the health professionals

Method: We referred to the section 50 and 51 of the *Global action plan on the public health response to dementia 2017-2025* and developed 3 strategies to reach the goal.

1. Training the health professionals:

“Zhongzheng District Health Center, Taipei City” is a primary health center that keeps the residents of Taipei, Taiwan away from getting infectious and noncommunicable diseases. We held training courses about prevention and management of diabetes for all nurses working in the health center in order that the nurses can proactively manage diabetes risk factors when conducting counselling about risk reduction.

2. Promoting physical activity:

Through health screening by the nurses, we recruited people with physical inactivity, high blood pressure, high blood cholesterol level and other health status prone to diabetes to attend the health promotion course for prevention of diabetes. During the course, we promoted the concept of doing at least 150 minutes of moderate-intensity aerobic physical activities per week, suggested by WHO, and invited physical therapists to instruct the participants in evidence-based exercise protocols and how to exercise without injuries. Furthermore, we took the participants to the parks near their home to exercise in order to creating lifestyle patterns of exercising regularly.

3. Promoting healthy and balanced diets:

The participants mentioned above also underwent diets interventions during the course. We developed the “diet book” to record what they ate, providing a way of keeping track of calorie intake and the number of servings of the 6 basic food groups. In addition, we have advocated the Mediterranean diets, shown to be protective against dementia, cardiovascular and several chronic diseases. With the help of nutritionists, the participants designed healthy recipes, facilitating them to put the concepts of healthy and balanced diets and the Mediterranean diets into practices. We checked the blood sugar and HbA1c of the participants regularly to evaluate the efficacy of the strategies.



POSTER ABSTRACTS

Result: All the 11 nurses passed the written examination of the Diabetes Shared Care Network, certificated by Taipei City Government. 22 participants attended the health promotion courses. 81.8% of them have remained the lifestyle of exercising at least 150 minutes of moderate-intensity per week for 1 year. 10 recipes were designed. They also shared successful tips about conducting health promotion, making the connection between them more closely. All of them did not become diabetic revealed by blood sugar and HbA1c examinations followed for 1 year.

Conclusion: The results indicate that the health promotion course can prevent people with risk factors of diabetes becoming diabetic, providing a way to contain the prevalence of diabetes and a possible model to control other noncommunicable diseases, which are indicators of the action “dementia risk reduction” of the *Global action plan on the public health response to dementia 2017-2025*.





P18-001

DIGITAL SELF-MONITORING FOR PEOPLE WITH MILD COGNITIVE IMPAIRMENT: THE 'MONITOR-MI' STUDY

Ms. Sara Laureen Bartels^{*1}; Rosalie van Knippenberg²; Frans Verhey² and Marjolein E de Vugt², (1)Department of Psychiatry and Neuropsychology, Maastricht University, Maastricht, Netherlands, (2)Maastricht University, Maastricht, Netherlands

Abstract:

Objective: Research investigating on daily functioning, emotions, behavior and cognition in people with mild cognitive impairment (MCI) normally uses retrospective measures. Ecologically valid information on how people with MCI perceive and react to challenges on a daily basis is lacking. The Experience Sampling Methodology (ESM) is an innovative technique that is specifically appropriate to collect information in everyday life. ESM can reveal pattern of activities and context, related emotions as well as their fluctuations in daily life. To our knowledge, ESM has not been used in MCI yet. Therefore, the primary objective is to evaluate the feasibility and validity of the ESM, specifically implemented in the PsyMate smartphone application, in an MCI population.

Method: 30 participants will be asked to collect ESM data using the PsyMate application on a smartphone over a six-day period. The application will generate eight signals/day at unpredictable moments between 07:30 and 22:30h. After each signal, short reports of the current mood, subjective cognition, context (activity, company, location) and appraisals of the situation will be collected. Furthermore, a morning and evening questionnaire will ask the participant to reflect on the last night/day. Before the ESM data collection, participants will be asked to fill out a number of retrospective questionnaires concerning e.g. their cognition, activities of daily living, perceived stress and psychiatric symptoms.

Feasibility will be assessed by examining compliance with the PsyMate application as well as through subjective participants' ratings of the difficulty, time burden and overall acceptability of the methodology. An observation of the individual performing the application on the smartphone will give further insight.

Validity will be assessed by examining the presence of expected patterns among variables in daily life of the person with MCI and by examining the concordance between ESM measurements and standard retrospective measurements of the same construct.

Result: Data collection will start in February 2018 and preliminary results are expected by June 2018.

Conclusion: ESM real-life information of people living with MCI may enable the individual, caregiver, clinician as well as research to better understand the condition of the person with MCI. Furthermore, ESM as part of an intervention has the potential to promote self-management abilities and modify behavior towards more meaningful and positive activities. This promising self-monitoring smartphone approach could prospectively contribute to an increased patient ownership in therapy. Evaluating the feasibility and validity of the ESM delivered via a smartphone application could thus be an important initial step to develop an innovative technology based intervention to assist people with MCI to self-manage everyday life.





POSTER ABSTRACTS

Technology, innovation and entrepreneurship - Poster

P18-002

INFORMATION TECHNOLOGY AND INTERNET OF THINGS TO IMPROVE CARETAKERS EFFICIENCY AND REDUCE INFORMATION ASYMMETRY

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Abstract:

Taiwan is the fastest ageing region in the world. The population with dementia is at 1.3% of the overall population in Taiwan and the number is growing rapidly. High human resource costs and information asymmetry are two major problems causing inefficiency in performing services required by the ones with dementia. The author believes information technology (IT) is the key tool to overcome these obstacles.

In Taiwan, the steps for a person with dementia to request services are assessment, assigning, performing, recording and billing. When one with dementia requires assistance, he/she has undergone assessments by professional evaluators, mainly government employees, to determine types of services helpful to the person. A service provider, which is geographically close to the person, is assigned. After services delivery, the service providers have to leave detailed paper trail. Every month, the service providers gather all these paper works to claim payments from the government. Government officials literally go through every record manually to confirm if there is any mistakes or fraud involved. At least 1.5 months after, the service providers will receive the payments. All these processes create unnecessary work load and processing time where extra human resources are arranged to administrative works instead of actually "caring".

Information asymmetry between caretakers and care receivers generate dangers and low quality of services. At 7:21 on a morning of August in 2017, the author arrived at the dementia day service center he operates and the center usually opens at 7:40 when is about 20 mins before the elderlies arrive. However, the sight of seeing a lady with mid-stage dementia sitting outside the parking lot gate seriously scared the author. The author swiftly opened the gate and parked the car. The first thing the lady said to him was "The ATM machine is broken", when there is actually no ATM machine anywhere near the center. However, the author didn't correct the lady and quickly led her entering the center. The staff of the first shift arrived and the first thing she said was "where is the other grandma?". At this moment, the author's world was really crumbling because two people with dementia were in serious danger. After a few phone calls with the family members, the author found out that the lady, who arrived early, lives with her second daughter who has grown impatient. On the previous night, the grandma kept requesting a trip to ATM. The daughter simply gave the mother a piece of paper written with the center's address. Grandma got up the next morning, dressed up nicely, stopped a taxi, and arrived at the center all by herself. This is why the grandma showed up way before the staff arrived in the morning and had the risk of getting lost. It would be possible to avoid potential risks if the caretakers were able to know the events taking place at homes and adjust services accordingly.

Management software enhance the efficiency of human resources and internet of things(IoT) devices collect spontaneous data which is essential to fully understand how symptoms of dementia alter one's behavior. The implementation of management system to different service providers across different cities in Taiwan shows dramatic improvement of service efficiency by reducing all unnecessary workload. Also, the IoT devices deployed in elderlies' home have shown promising data which will allow caretakers to provide more personalized services based on objective evidences.



P19-001

ACCEPTABILITY AND FEASIBILITY OF WEARING ACTIVITY MONITORS IN COMMUNITY-DWELLING OLDER ADULTS WITH DEMENTIA

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Abstract:

Introduction: Measuring physical activity is a complicated particularly in people with dementia, where activity levels are low and subjective measures are susceptible to inaccurate recall. Activity monitors are increasingly being used within research for people with dementia, however, it is unclear how people with dementia view wearing such devices.

Objectives: To evaluate the acceptability and feasibility of people with dementia wearing activity monitors.

Methods: Twenty-six, community-dwelling, people with dementia were asked to wear an activity monitor (GENEactiv Original) over a one-month period. Perceptions of the device were measured using the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) 2.0, alongside qualitative interviews taken at the end of study. Device diary and activity monitor data was used to assess compliance.

Results: Participants tended to find wearing the activity monitors acceptable, with only three participants (11.5%) withdrawing prior to the study end date. Participants were generally satisfied with wearing the devices as measured by the QUEST (Mdn = 4.4, IQR = 1.1). Four themes were identified to influence perceptions of wearing the device: external influences, design, routine and perceived benefits.

Conclusion: Getting people with dementia to wear a wrist-worn activity monitor for prolonged periods appears to be both feasible and acceptable. Researchers need to consider the needs and preferences of the sample population prior to selecting activity monitors

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POSTER ABSTRACTS

Environment and technology - Poster

P19-002

EXPLORATION OF PRINCIPLES FOR BUILDING A SMALL-SCALE MULTIFUNCTIONAL COMMUNITY FOR INDIGENOUS PEOPLE - A CASE STUDY IN TAITUNG, TAIWAN

Teng-Yi Wang¹; Ting-Yu Yeh²; **Po-Tsung Chen**^{1,2} and Teng-Yi Wang Ms^{2,3}, (1)Institute of Occupational Therapy, National Cheng Kung University, Tainan, Taiwan, (2)Institute of Gerontology, National Cheng Kung University, Tainan, Taiwan, (3)United Kingdom

Abstract:

Objective: When aged society is coming, how to provide local care for elders in indigenous community with insufficient resources has become the main concern. We aimed to explore the principles for building small-scale multifunctional facilities in indigenous communities to satisfy the elders' needs.

Method: At first, we used literature review to explore possible models of "successful aging" and "aging in place" for indigenous people, and identify characteristics of communities that are recognized by the local elders. After that, we collected the elders' concerns about "integration of community resources" and "recognition of another home" in community by interviews. Elders who live in the Yanping Township, Taitung County, Taiwan were interviewed. Finally, the expert panel summarized the principles for building an ideal community based on the results of literature review and the elders' consideration.

Result: Following principles were found to be important for building a small-scale multifunctional care facility in indigenous communities: 1. Provide an entrance image as at home. 2. Provide a small and flexible lifestyle care unit. 3. Provide a diverse family space and function. 4. Provide an open-air kitchen for preparing local meals. 5. Provide toilet space which will promote independent behavior. 6. Prudent to use local culture totems. 7. Provide an outdoor and natural green combination of living space. 8. Consider the semi-outdoor space in response to the local climate. 9. Need to provide a reviewed and recommended mechanism for local community residents to participate in. 10. Consider the integration of local community resources for the total community construction and assistant of life.

Conclusion: Conceptually, the best care for indigenous elders can only be achieved by providing good hardware facilities and adopting modes of local living care. We proposed the 10 principles that can provide useful information for care providers to build a good community to facilitate "aging in place" and "cultural heritage".



Environment and technology - Poster

P19-003

AN ANALYSIS OF THE RESULTS OF THE QUESTIONNAIRE ON TRAFFIC SAFETY GIVEN TO PEOPLE WITH DEMENTIA AND FAMILY CAREGIVERS IN JAPAN.

Ms. Naoko Hara^{*1,2}; Kazuo Kariyama^{2,3}; Motoharu Kawai^{2,4}; Haruyuki Kamata²; Kazuyo Hasegawa²; Kyoko Eguchi^{2,5} and Ms. Noriyo Washizu², (1)Nursing, Niigata College of Nursing, Jyoetsu, Japan, (2)Alzheimer's Association Japan, Kyoto, Japan, (3)Occupational Therapy, Bukkyo University, Kyoto, Japan, (4)Neurology, Yamaguchi University, Yamaguchi, Japan, (5)Nursing, Shumei University, Yachigo, Japan

Abstract:

To create for the dementia friendly society, we investigated the response of family carers who have experiences of disappearance, wandering, and driving accidents or trouble with the return of the licence related to dementia in Japan. According to police report in 2016, a number of missing person with dementia was 15 thousand in Japan. The government revised Road Traffic Law to strengthen the regulation on older drivers and implemented in MAR. 2017. By this law a person dementia have to return his/her driving licence. We will discuss the way of lower stress on traffic safety for people with dementia and family caregivers, because the person with dementia and their families has haven more stress-full.

The questionnaires were provided each 20 for prefectures of all Japan through our 47 regional branches in Jan 2018. Contents were Characteristics of people with dementia and respondents, experienced accidents, the main mobility device for outgoing, the way for searching at disappearance, the response for wandering or driving before/after the accident, the way to return the driving licence. The Executive Committee of our corporation had given this investigation a permission.

At 7th FEB. 2018, reply data were corrected 394, time limit is 9th FEB. we disclose the way or response them by descriptive statistics, and exhibit some regional case reports. On the several response, they cost about more than 600 dollars for wandering by automobile. In other cases, they had depressed and became irate after return the licence, on the other hand, they had taken down driving himself.

We discuss about the burden these accident for people with dementia and their families, in addition to want to suggestion new stress-free mobility device for people with dementia and their families and their supporters. This investigation was supported by Tokio Marine & Nichido Fire Insurance Co., Ltd.



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Environment and technology - Poster

P19-004

FROM TRANQUIL TO VITAL: FULL-SPECTRUM LIFE IN RESIDENTIAL CARE

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Abstract:

Faced with aged and outmoded facilities serving 629 residents on five sites in Vancouver, Providence Healthcare (PHC) launched an innovation and improvement initiative called *Residential Care for Me*. The first phase of implementation, with Stantec providing integrated design services, would be a new 320-resident dementia care facility on an urban site, developed with deep engagement of resident, families and a 40-person steering committee. A field study was scheduled just prior to completion of the needs assessment and design concept. Eleonore and Ray were

part of a 4-person Providence Health Care/Stantec team that visited 17 residential care homes in Switzerland, Germany, the Netherlands, Sweden and Finland. They will summarize the learnings from the field study and the essential characteristics of the social, spatial and activity model that has been adopted for a resident-supportive and socially generative residential care home based on small households, including, complete freedom of movement. The presentation will conclude with a virtual tour of the proposed 320-bed facility design explaining how the essential characteristics have been realized.





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EEEnvironment and technology - Poster

P19-005

DELIVERING COGNITIVE STIMULATION WITH TECHNOLOGY

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Abstract:

Objective: CIRCA (Computer Interactive Reminiscence and Conversation Aid; Alm et al., 2004) is an interactive, multimedia system to support conversation between people living with dementia and care partners (Astell, et al., 2010). CIRCA is supplied with photos, music and videos, is easy to use and requires no preparation by staff. The potential of CIRCA to deliver cognitively stimulating group-based activities in day and long-term care settings has not previously been explored.

Method: One hundred and sixty people living with dementia have been recruited from 11 sites across the UK as part of an EU Horizon 2020 project. Half have been using the existing standalone CIRCA device and half a new web-based version. Pre-, post- and three-month post-intervention primary outcome measure: Addenbrookes Cognitive Examination-III (ACE-III; Hsieh, 2013; /100), with QOL-AD (Logsdon, et al., 2003; scored between 13-52) and EQ-5D (/100) as secondary measures. All group sessions were video-recorded to provide qualitative assessment of engagement, enjoyment and social interaction within the groups.

Result: Of the 160 participants, 145 (26 males, 119 females) have completed the 8-session programme and pre- and post-measures, of which 45 have also completed the three-month follow up. These 45 (7M, 38F) are aged between 69-97 years, 41 live in long-term care, with ACE-III scores at baseline between 6-84 (mean 48.3), QOL-AD scores between 21-41 (mean 31.24) and EQ-5D between 15-100 (mean 65.11). Preliminary analysis revealed a significant improvement in cognitive function over the three time points, ($p=0.01$), with significant increases from baseline to post-intervention ($p=0.05$) which was maintained at 3-month follow up ($p=0.005$). There was also a significant increase in quality of life scores over the three time points ($p=-0.001$).

Conclusion: Participation in the CIRCA group sessions led to improved cognitive scores which were maintained at three months follow up, along with improved quality of life similar to those reported for cholinesterase inhibitors. The videos of the CIRCA groups sessions highlight the opportunities for enjoyment, engagement and social interaction. The data so far confirm the potential of CIRCA, an easy-to-use interactive multimedia system, as a cognitively-stimulating group-based activity for individuals in day and long-term care, including those with significant cognitive impairment (lower ACE-III scores). The web-based version of CIRCA, which can be populated with contents from any culture or country and labelled in any language, is being trialled in Sweden, Spain and the Netherlands.

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POSTER ABSTRACTS

Environment and technology - Poster

P19-006

PERSONS WITH DEMENTIA SAFETY IN DEVELOPING COUNTRIES: ASSISTIVE TECHNOLOGY AND INTERNAL ENVIRONMENT

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Abstract:

Objective: Exploring how to fulfill safety of persons with Dementia especially in Developing countries

Method: Theoretical and Analytical

Result: Through the use of Assistive Technology and careful design of internal environments we achieve our aim.

Conclusion: Developing countries need to encourage more research leading to more awareness about the issue, about ways of dealing with persons with dementia and more expertise in the field of Assistive Technologies.

Dementia is a syndrome that leads to deterioration in memory, thinking, behavior and the ability to perform activities. It is caused by a variety of brain illnesses.

As researches and statistics revealed the wide spread and high prevalence of dementia worldwide, as well as the speed of its expansion, - a person is diagnosed with the case every 3.2 seconds [1]-, the number of persons living with Dementia Globally reached 47.5 million in 2015. There is a need, then, for greater attention and more care to be allocated to persons living with Dementia and more support for their families and care givers.

Dementia cost was 818 billion US dollars in 2015 of which 86% was measured in High Income countries. The main factor leading to this rise in Dementia cost is the increase in the number of persons with Dementia. The rise is cost per person although "Low income countries account for 1% of the total worldwide costs and 14% of the prevalence of dementia cases, while Middle income countries account for 10% of the costs and 40 % of the prevalence of dementia cases and high income countries account for 89% of the costs and 46% of the prevalence of dementia cases. Two main regions of the world that include Western Europe and North America account for 70% of the global costs of Dementia" [2].

All these data reveal the importance of providing ways to assist in facilitating care for these persons, while enabling them to maintain their independence, perform their daily living activities, manage the risks they could face at home, and reduce their families stress. Therefore, it is urgent to secure the safety of these individuals through the use of Assistive technologies as well as Internal Environment Design.

Through a theoretical review of literature and an analytical approach this research paper aims at exploring how the use of Assistive Technology together with a carefully studied design of the internal environment could help Persons with Dementia live a safer and more rewarding life.

Key words: Dementia; Prevalence of Dementia; Assistive Technology; Internal Environment Design; Developing Countries.



P19-007

RESEARCH ON THE APPLICATION OF ACCESSIBLE FACILITIES TO ASSISTING THE SELF-RELIANT BEHAVIOR OF PATIENTS WITH DEMENTIA - A CASE STUDY OF GROUP HOME IN TAICHUNG

Po-Tsung Chen^{*1}; Dinchan Shieh²; Yating Wang² and Lingyu Su², (1)Institute of Gerontology, National Cheng Kung University, Tainan, Taiwan, (2)Herbert P.T. Architects & Associates, Tainan, Taiwan

Abstract:

Objective: In recent years, Taiwan has been working on the research of how to make the patients with dementia to feel safe, convenient, comfortable and put off the course of disease in the living environment of the group home by constructing a barrier-free environment. The purpose of this research is to discuss the advantages of the self-reliant behaviors result from applying the accessible facilities in the living environment for patients with dementia in group home. The solutions for improvement and measures will be proposed.

Method: In-depth interviews, observation method and focus group discuss are adopted in this research. In addition, with three principles of enhancing self-reliance, safety and daily life continuity, 16 patients with dementia who are living in group home in Taichung and the environment which they live are observed to explore the key points that must be considered when applying accessible facilities to the environmental design or renovation.

Result: The research results show that the following points shall be considered when applying barrier-free facilities to patients with dementia to enhance their self-reliance: (1) control the light to avoid glare (2) eliminate roadblocks to avoid falling (3) provide clear indication of the direction (4) eliminate height differences to ensure safe horizontal movements (5) Set the traffic flow for handrail extension (6) strengthen the space identification with color scheme (7) set help system to strengthen the assistance.

Conclusion: To sum up, the living environment for patients with dementia needs to be reviewed and renovated according to their physical and mental status. Only by making the environment itself the support for the patients to continue their self-reliance can we realize the development of self-reliant behavior.

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Environment and technology - Poster

P19-008

COMPARATIVE ANALYSIS BETWEEN TELEMEDICINE-BASED CARE AND DIRECT CARE ON INSTITUTIONALIZED DEMENTIA CARE FACILITIES IN TERMS OF COST EFFECTIVENESS AND QUALITY OF CARE IN INDIAN POPULATION

Radha S Murthy^{*}; S Premkumar Raja; Swetha Nagraj; Smitha K; Chanemougasoundharam Arunachalam; Swati Bhandary; Sruthi Sivaraman and Baishakhi Ghosh, Nightingales Medical Trust, Bengaluru, India

Abstract:

Background:

The World Health Organization's Mental Health Atlas (2011), states that India's mental healthcare is underfunded¹. India spends about 0.06% of its health budget on mental healthcare. India has a psychiatrist to patient ratio of 1 psychiatrist for every 3,43,000 patients. According to India's Health Ministry, 6 to 7% of India's population suffers from psychosocial disabilities (~75 million people). About 70% of the elderly population of India reside in rural or remote areas. Due to which, the accessibility to mental healthcare professionals and services in rural area is limited. Telemedicine holds the potential to significantly impact these challenging problems in Indian population.

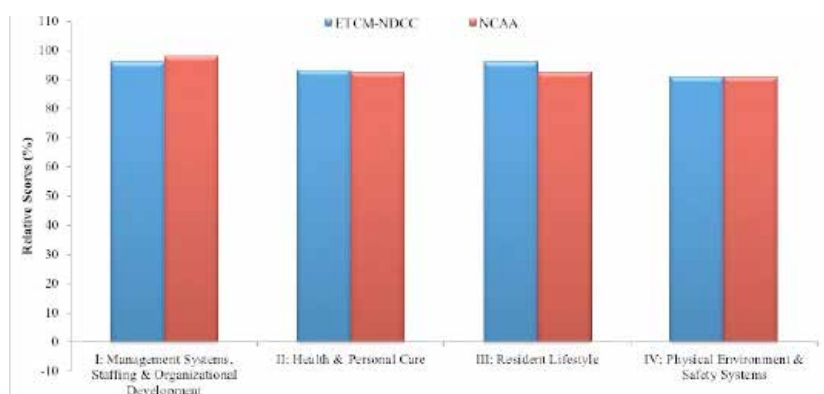
Research gap:

In western population, telemedicine applications are found to be cost effective and have been developed to assess the patients with Dementia (PWD) and caregivers, evaluate the cognitive changes in PWD, design treatment plan for PWD and support the family caregivers of PWD. In India, telemedicine is an emerging technology that is limited to consultation and assessing the PWD. However, there is lack of published evidences in Indian population that had implemented and analyzed the efficacy of telemedicine-based care intervention in Dementia care facilities.

Objective: The objective of the study was to compare the efficacy of the telemedicine-based care intervention with that of direct care intervention on institutionalized Dementia care facilities in terms of cost effectiveness and quality of care in Indian population.

Method: In this study, we compared 2 residential Dementia care facilities of Nightingales Medical Trust (Bengaluru, India) receiving either telemedicine-based care intervention or direct care. Ellen Thoburn Cowen Memorial – Nightingales Dementia Care Centre (ETCM-NDCC: a 48-bedded facility, located in semi-urban Kolar town, India) received telemedicine-based care intervention, whereas, Nightingales Centre for Ageing & Alzheimer's (NCAA: a 100-bedded facility, located in urban Bengaluru, India) received direct care intervention. The cost of care for both the interventions were compared and the quality of care was assessed by Quality Dementia Care Standards (QDCS) questionnaire (ADI, 2007)². The QDCS questionnaire was administered by trained psychologist on 30 randomly selected family members of the PWD, who have availed these residential care facility (15 from ETCM-NDCC and 15 from NCAA).

Results: We found that there was no statistical significant difference in the QDCS (Standard I: Management





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systems, staffing, & organisational development, Standard II: Health & personal care, Standard III: Resident lifestyle, and Standard IV: Physical environment & safety systems) between the telemedicine-based care and direct care interventions ($P>0.05$) (Figure 1). However, with the telemedicine-based intervention, the cost of providing Dementia care reduced by 33%.

Conclusion: This study indicates that the telemedicine-based care intervention reduces costs without affecting the quality of Dementia care and increases accessibility to Dementia care services. It is possible that the telemedicine-based care approach can also be implemented in rural and remote areas, where access to direct care intervention is difficult.

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Environment and technology - Poster

P19-009

USABILITY OF ELECTRONIC PATIENT RECORDS FOR ASSESSMENT AND CARE PLANNING FOR PEOPLE WITH DEMENTIA IN NURSING HOMES: PROTOCOL AND PRELIMINARY RESULTS

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Abstract:

Objective: Nursing homes are more frequently turning to the electronic patient record (EPR) to manage documentation. Potential benefits associated with EPR include the storage of longitudinal information, interoperability, and improved documentation quality. However, the uptake of EPR in nursing homes has varied considerably across countries, which has been associated with the incompatibility of some EPR systems with this environment. Furthermore, the suitability of EPR for planning dementia care is largely unknown. The objective of this study is to produce recommendations for the future development of EPR systems for use in the assessment and care planning for people with dementia in nursing homes.

Method: Case studies of four nursing homes using EPR in Belgium, Czech Republic, Spain and the UK will be conducted. There are two elements to the study: (i) the contextual inquiry method will be employed to explore usability issues with different types of end users. Data will be analysed using qualitative content analysis; (ii) the electronic care plan used in each of the homes will be compared with best practice guidance for dementia care planning in order to explore the extent to which they include aspects of care that are relevant for people with dementia.

Result: Primary data collection will be ongoing throughout 2018, and results will inform recommendations for the future development of EPR systems for use in the assessment and care planning for people with dementia in nursing homes. These recommendations will address the most suitable components of an EPR system, such as the type of device and applications, as well as structure, content and functionality.

Conclusion: It is anticipated that the results of this study will lead to a reduction in usability issues associated with EPR for assessment and care planning for dementia, and subsequently, increased adoption and more successful implementation of EPR, as well as improved care for people with dementia in nursing homes. Recommendations will form part of the broader European project 'Interdisciplinary Network for Dementia using Current Technology' (INDUCT), which aims to produce guidelines on human interaction with technology and dementia.



P20-001

INCIDENCE OF COGNITIVE IMPAIRMENT IN PATIENTS WITH CEREBRAL VASCULAR EVENTS IN MEXICAN HEALTH AND AGING STUDY 2012-2015

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Abstract:

Objective: Cognitive impairment (CI) associated with cerebrovascular disease (CVD) is considered the second most common cause of dementia. Depending on diagnostic criteria, the annual incidence of vascular CI varies from 0.99/1000 (CI: 0.96-1.02) to 9.5/1000.

The aim of this study was to estimate the incidence of CI in patients with CVD and to determine associations with common risk factors.

Methods: The MHAS (*Mexican Health and Aging Study*), a survey with national representation of Mexican older adults, included 15,723 participants in its third round in 2012 and 14,779 participants in its fourth round in 2015. Incidence rates were calculated. Univariate and multivariate logistic regression models were conducted to determine the association between Cognitive Impairment and Cerebrovascular disease and common risk factors. Associations were considered significant at the 0.05 level.

Results: In patients with CVD, the incidence of new cases of CI was 4.0% (CI 2.0-7.3) per year. There was an increased risk of CI associated with the presence of female sex OR 1.34 (CI: 1.11-1.62), $p = 0.02$, type 2 diabetes mellitus, OR = 1.30 (CI: 1.06-1.60) $p = 0.01$ and depression OR = 1.52 (CI: 1.24-1.87) $p < 0.001$.

Conclusion: There are few epidemiological studies in Mexico that determine the incidence of CVD and CI in older adults. In the group that developed CI, there was an association with expected risk factors, such as female sex and the presence of type 2 diabetes mellitus and depression.

Table 1. Multinomial logistic regression in comparison with the control group (n=5,369)

	Cognitive Impairment (CI) N=511			Cerebro-Vascular disease (CVD) N=58			CI + CVD N=8		
	OR	IC	p	OR	IC	P	OR	IC	p
Age	1.01	1.00-1.03	0.03	1.02	0.98-1.06	0.20	1.07	0.97-1.17	0.15
Female Sex	1.27	1.05-1.54	0.01	0.89	0.53-1.51	0.68	0.27	0.05-1.39	0.12
Diabetes	1.29	1.05-1.59	0.01	0.78	0.40-1.51	0.46	0.57	0.07-4.73	0.60
Obesity	0.76	0.61-0.96	0.02	1.77	1.02-3.09	0.04	0.56	0.06-4.67	0.59
Depression	1.45	1.18-1.80	<0.001	1.31	0.71-2.43	0.37	1.77	0.35-8.99	0.48



POSTER ABSTRACTS

Epidemiology - Poster

P20-002

DIETARY STUDY IN CUBAN ELDERLY WITH ALZHEIMER'S DISEASE (AD) OR MILD COGNITIVE IMPAIRMENT (MCI)

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Abstract:

Objective: To compare the intake of some foods between the groups: normal subjects, with MCI and AD and to evaluate the association between inadequate intake of food with the studied groups in Cuban elderly.

Method: Cross sectional study in 424 subjects older than 65 years; 43 with AD, 131 with Mild Cognitive Impairment (MCI) and 250 normal subjects from Havana City. Dementia was diagnosed using the 10/66 Dementia and DSM-IV criteria and MCI with the Hughes Clinical Dementia Rating. Diet was evaluated using a weekly food-frequency questionnaire. Pearson's Chi square and prevalence ratios were used for data analysis.

Result: Food intake was not different between studied groups, with exception that cereals and tubers intake was lowest in AD group. Fish, grains+fruits, vegetables, fats intake was inadequate in 80%, 60%, 50%, 50 % respectively, in the subjects of the three groups.

Conclusion: High frequency of older adults of three groups had insufficient intake of fish, grains+fruits, vegetables and fats. Only the insufficient intake the cereals and tubers was associated significantly with the prevalence of AD.





POSTER ABSTRACTS

Epidemiology - Poster

P20-003

PROFILE OF PEOPLE WITH DEMENTIA FROM A TERTIARY CARE CENTER IN KARACHI, PAKISTAN

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Abstract:

Objective: To study profile of people with dementia from a tertiary care hospital in Karachi, Pakistan.

Methods: Data was collected from records of people who presented to the outpatient clinic in Psychiatry department at the Aga Khan Hospital, Karachi from January 2015 until January 2016. DSM-IV TR was used to diagnose dementia. A questionnaire was designed to collect demographics, co morbid conditions, neuropsychiatric symptoms, family history, presence or absence of imaging, and MMSE scores.

Results: Total number of people with dementia was 100. Mean age was 66 ± 27 years and 56% were females. 25% of the patients had more than 14 years of education and family history was positive in 39%. The type of dementia most commonly diagnosed was Alzheimer's disease accounting for 63 % of total cases. 54% of all dementia patients had hypertension, as co-morbid condition. Depression was the most common neuropsychiatric symptom present in 41% of all dementia cases.

Conclusion: The clinical characteristics, presentations, and demographics of people with dementia are not very well explored in Pakistan. This study explored features such as mean age of presentation, gender, education, and common symptoms of dementia in a tertiary care setting in Karachi, Pakistan. More clinical data and registries are needed to address specific needs of this population.





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