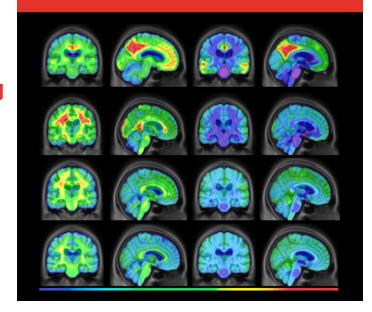
Alzheimer's Disease International



World Alzheimer Report 2021

Journey through the Diagnosis of Dementia



Welcome and Introductions





Paola Barbarino CEO,

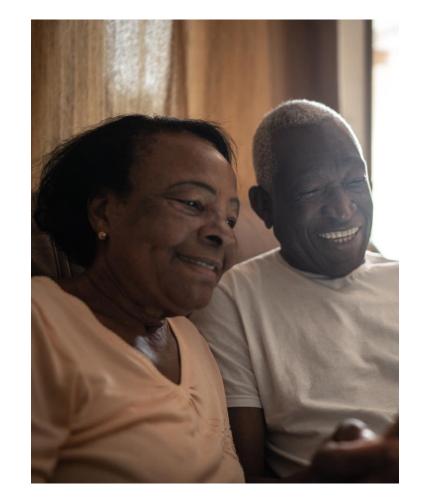
Alzheimer's Disease International (ADI)

@AlzDisInt

About ADI



- Established in 1984
- Umbrella organisation of Alzheimer and dementia associations around the world - 105 full members associations and federations, only one per country. Over 20 in development
- We represent you all at the WHO, the UN, OECD and other global and regional bodies
- Promoter of World Alzheimer's Month
- Publisher of the World Alzheimer Report and others



Our vision is prevention, care and inclusion today, and cure tomorrow



Know Dementia, Know Alzheimer's





September 2021

Know Alzheimer's The importance of a timely diagnosis



#KnowDementia #KnowAlzheimers
#WorldAlzMonth www.worldalzmonth.org

@@alzDisInt @@alzDisInt \$\infty\alzDisInt



Please interact with our social media accounts to spread the voice of World Alzheimer's Month:







#KnowAlzheimers #KnowDementia #WorldAlzMonth

Thanks to our Sponsors



Van Otterloo Family Foundation





















The Mary Oakley Foundation

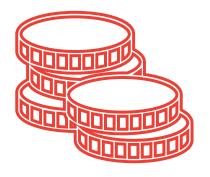


Donate



We will not rest until dementia is properly acknowledged as the epidemic it is.

Your donation can help us get there faster.



www.alzint.org/donate

Speakers

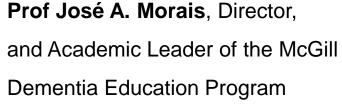












Prof Suvarna Alladi, National Institute of Mental Health and Neurosciences, India



Roger Marple, Person living with dementia, Canada



Dr Rufus Akinyemi, Deputy Director, Centre for Genomic and Precision Medicine, College of Medicine, Nigeria



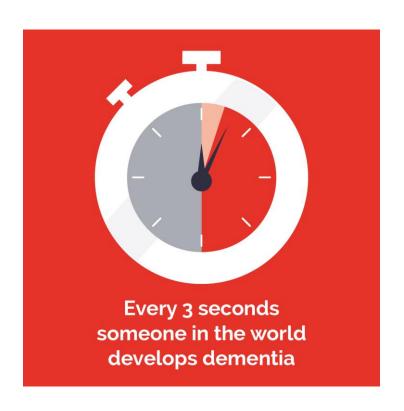
Prof Pedro Rosa-Neto, Director,
McGill University Research Centre
for Studies in Aging

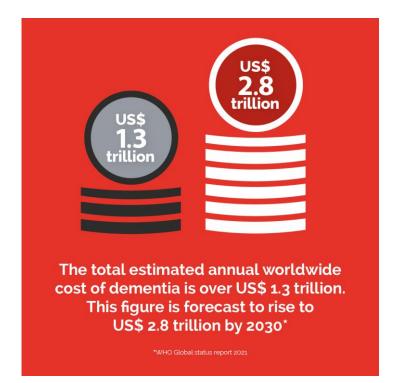


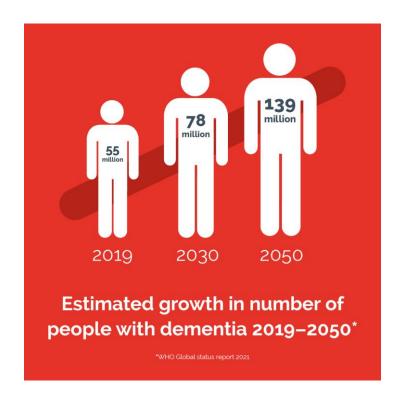
Claire Webster, Founder and Ambassador,
McGill Dementia Education Program and
Founder and President, Caregiver Crosswalk

The global impact of dementia









WHO's Global action plan on dementia



Dementia as a public health priority



Dementia awareness and friendliness

Information

systems for

dementia



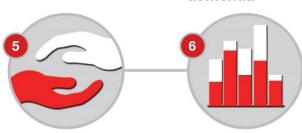
Dementia risk reduction



Dementia diagnosis, treatment, care and support



Support for dementia carers



Dementia research and innovation



Towards a dementia plan: a WHO quide

WHO target: In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025

World Alzheimer's Month 2021 Know Dementia, Know Alzheimer's





- The theme for the 2021 campaign is Know Dementia, Know Alzheimer's and was all about the power of knowledge.
- During the campaign, we are shining a light on the <u>warning signs of dementia</u> and the importance of a timely diagnosis
- Receiving a diagnosis of dementia is often a challenging and difficult process. To add to this, the stigma surrounding dementia means that many avoid seeking a diagnosis until the very late stages of the condition. We need to change this.

www.alzint.org/get-involved/world-alzheimers-month/

World Alzheimer's Month 2021 Know Dementia, Know Alzheimer's



FINANCIAL TIMES

Scientists warn that Covid will accelerate 'dementia pandemic'



CORONAVIRUS | News

COVID-19 could serve as a 'Trojan horse' for dementia and Alzheimer's, experts say

THE STRAITS TIMES

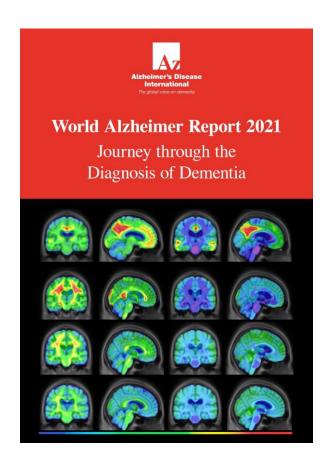
SINGAPORE

People with long Covid feared to be at risk of developing dementia







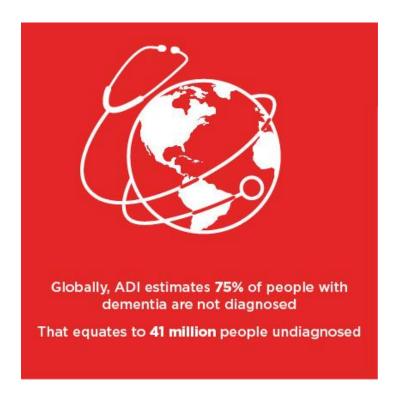


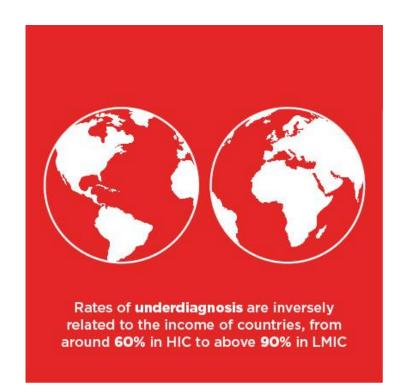
- This 2021 report is entitled: 'Journey through the diagnosis of dementia'.
- ADI commissioned McGill University, Montreal to deliver this 2021 World Alzheimer Report
- A global perspective on current dementia diagnosis practices, barriers and facilitators, emerging and imminent future impact of diagnostic breakthroughs and a robust set of recommendations required to improve the diagnosis journey across the world.

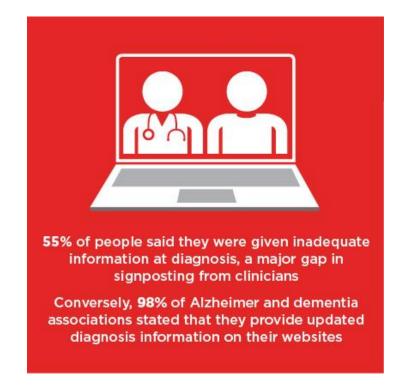
Suggested citation: Gauthier S, Rosa-Neto P, Morais JA, & Webster C.2021. World Alzheimer Report 2021: Journey through the diagnosis of dementia. London, England: Alzheimer's Disease International.

Rates of underdiagnosis are high





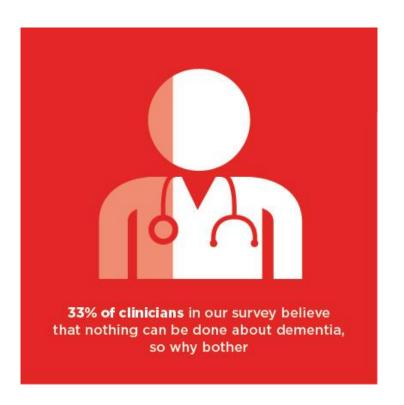




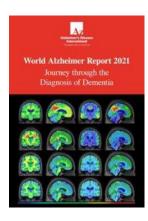
Stigma is correlated with underdiagnosis





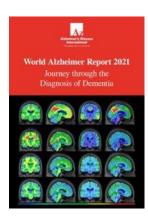


Selected recommendations



- Healthcare systems globally should introduce annual brain health check-ups for the over 50s, facilitated by evolution in biomarkers science, with the opportunity to promote risk reduction strategies.
- Governments globally must urgently start to measure and record diagnosis more accurately. Accurate measurement of diagnosis rates is the key to treatment, care and support, to healthcare system preparedness, and to challenging stigma.
- Governments must prepare for a tsunami of demand for healthcare services as a result of global ageing populations, improved diagnostics, including biomarkers, and emerging pharmacological treatments.

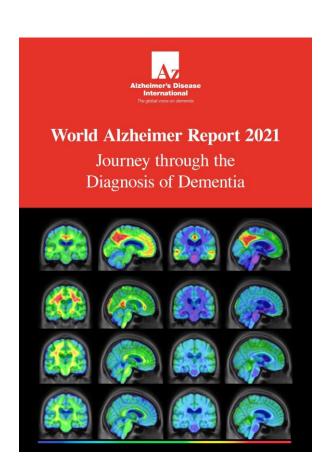
Selected recommendations



- Governments globally must recognise the right to a timely clinical diagnosis
 and put in place the capacity to deliver this, to enable better planning, treatment,
 care and support, in line with action area four of the World Health Organization
 (WHO) Global action plan on dementia.
- Further build on the innovative, often technology-based approaches, including telemedicine, which evolved rapidly during the COVID-19 pandemic, and research how these might best supplement, but not replace, future cognitive assessment, while acknowledging the benefits for remote or rural communities or for those unable to travel safely.

Full list of recommendations





The recommendations in full can be found at:

www.alzint.org/worldreport

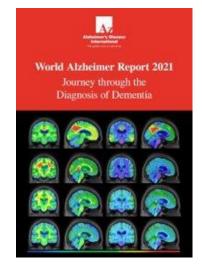
Professor Serge Gauthier





Professor Serge Gauthier

Professor Emeritus in Neurology and Psychiatry, Academic Lead, Dementia Education Program McGill University, Canada



The report itself is a journey through the diagnosis of dementia, including:

Expert essays: To encapsulate a broad range of knowledge, 113 healthcare professionals and researchers were invited to submit essays within their field of expertise and to contribute to the chapters.

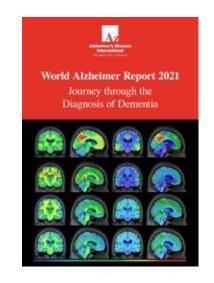
Surveys: The three surveys were conducted concurrently between March and June 2021 targeting people living with dementia and carers, clinicians and Alzheimer and dementia associations.

Testimonies: Individual case studies were requested from people living with dementia and 11 are included, covering all WHO regions. A larger set of videos accompanying this report can be found on ADI's YouTube channel.



This journey is brought to life through six sections:

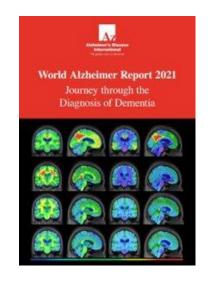
- Part I: Clinical assessment
- Part II: Laboratory tests
- Part III: Personal testimonies
- Part IV: Formulation of diagnosis
- Part V: Particular circumstances
- Part VI: The future of the diagnosis of dementia





The report contains survey data from a total of 3,431 respondents consisting of:

- 1,111 multidisciplinary clinicians in 108 countries (62% from high income countries and 38% from low- and middle-income countries)
- 205 people with dementia and 2,122 carers in 83 countries
- 101 Alzheimer's and dementia associations from around the world





Highlights from the clinician's survey



- Cognitive assessments are required for the diagnosis of dementia and to track changes over time.
- The cognitive screening tests most used by clinicians are the Mini Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA).
- Tests that overcome the influence of language differences are needed, such as the Visual Cognitive Assessment Test (VCAT).
- As a result of the COVID-19 pandemic, many clinicians have incorporated telemedicine into their practice.

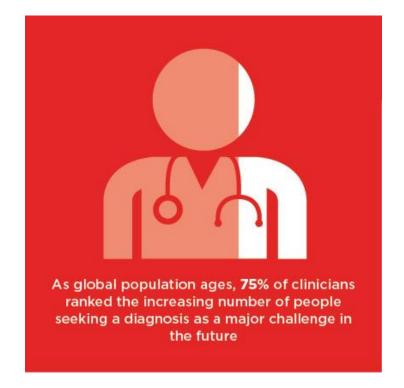


Covid-19 has exacerbated an already complex and time pressured diagnosis pathway





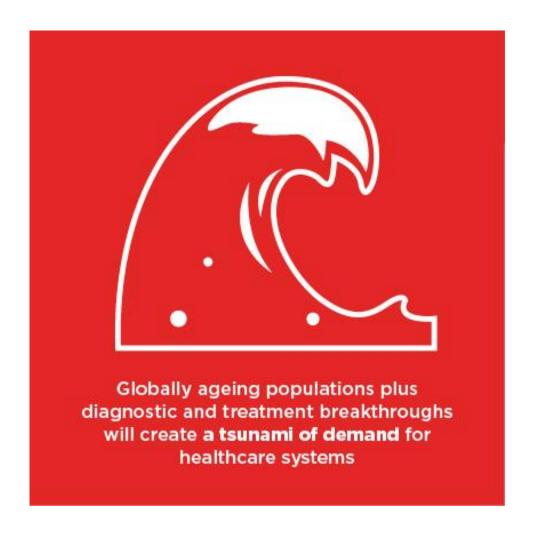






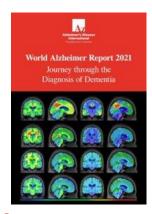
Health system preparedness needs to be improved







Selected recommendations



- Healthcare systems must make culturally appropriate, translated and validated cognitive assessment tools available to increase diagnosis rates, leading to better information and planning, plus access to treatments, trials and support.
- Call for a standardised, online, ethical, government adopted, cognitive assessment tools to enable people to take initial and informed steps and to mitigate against dangerous misinformation.
- Improved disclosure training required for diagnosing clinicians to communicate transparently and sensitively, providing information on next steps, clinical follow up, condition evolution, treatment options and, importantly, direction to post diagnostic support options.



Anders Wimo





Anders Wimo

Department of NVS, Centre of Alzheimer research, Section of Neurogeriatrics,

Karolinska Institutet, Sweden

New challenges and opportunities in the diagnosis of dementia



Anders Wimo, MD, PhD,

Family physician, primary care, Bergsjö, County of Gävleborg, Sweden

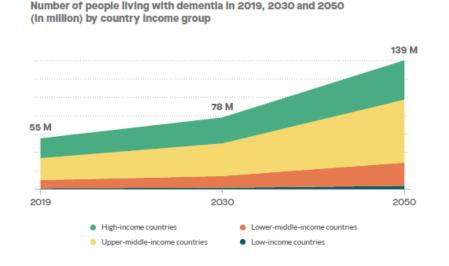
Professor Emeritus

Division of Neurogeriatrics and Aging Research Center, Karolinska Institutet Stockholm, Sweden

Today.....WHO report on dementia



- 55 million people with dementia worldwide
- 61% live in low and middle-income-countries
- Global cost 1.3 trillion US\$
- 50% of costs by informal care
- 74% of costs in high-income countries





Primary care and diagnostic work-ups in dementia



The ideal case: The family physician (a specialist in family medicine) has been working in the area for 10 years or more, is skilled in dementia, knows the patients and families very well, each visit takes 30-60 minutes, the list is maximum 1000 patients, family informants are available, a local dementia team (the GP, nurses, social workers etc.) is at hand and a basic dementia diagnostic work-up package is used (and remunerated).

The reality (often): full waiting rooms, the list is 3,000, the commission is broad, each visit takes 5-10 minutes, the GP is paid per visit, the GPs shift and skills vary a lot, all diagnostic tools are burdening the budget.

66

In many countries, primary care physicians see several patients per hour, perhaps 6–10, and it is not possible to make an accurate dementia diagnosis in 10 minutes.

The new challenges



- 1) Disease modifying treatments (DMT) for Alzheimer Disease is coming?

 The FDA (US) bomb this summer: Aducanumab (Aduhelm) got conditional approval
- 2) Prevention possible? The FINGER trial and "World Wide Fingers". Already part of primary care work
- 3) Consequently: The diagnostic boundary shifts from Dementia to "Pre-dementia stages": Prodromal (mild cognitive impairment) and pre-clinical. Type of cognitive impairment is crucial (Alzheimer's disease, vascular etc.).

The new problems



- Diagnostic capacity (RAND reports)
- Diagnostic accuracy risks of false positive cases
 - Example: prevalence 10%, sensitivity 90%, specificity 90%: Positive predictive value: 50%
 - Blood based biomarkers added : label "At risk", not "Early AD" without comprehensive diagnostic confirmation (specialists). Replace MMSE with MOCA??
- If disease modifying treatments (DMT) come: who will get it? Who pays (US\$56,000/year?)
- Global access to diagnostics and DMT?
 (Low middle-income countries)



The diagnostic infrastructure is not prepared for a large increase in demand for pre-dementia (and early dementia) Alzheimer's disease diagnostics.

Roger Marple





Roger Marple

Canada

Professor Pedro Rosa-Neto





Professor Pedro Rosa-Neto

Director, McGill University Research Centre for Studies in Aging

McGill University, Canada



Dementia is a late stage of brain diseases



(2) Toxic effects of dysfunctional proteins in the brain

Alzheimer's disease (AD)

Location: temporaparietal cortex Predominant Proteinopathy: Aβ plaques and tau tangles (3R:4R)

Parkinson's disease (PD)

Location: midbrain
Predominant Proteinopathy: Lewy bodies

Amyotrophic lateral sclerosis (ALS)

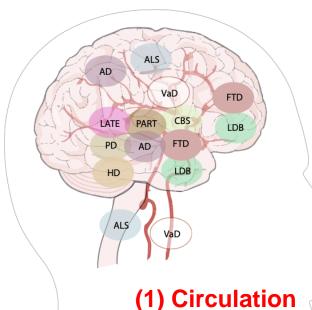
Location: Motor cortex, brainstem, spinal cord Predominant Proteinopathy: TDP43, FUS

Limbic-predominant age-related TDP-43 encephalopathy (LATE)

Location: Limbic
Predominant Proteinopathy: TDP43

Corticobasal syndrome (CBS)

Location: sensory and motor cortices, basal ganglia Predominant Proteinopathy: Aβ plaques and tau tangles (3R:4R) and tau tangles (4R)



Huntington's disease (HD)

Location: basal ganglia
Predominant Proteinopathy: poliQ inclusions

Frontotemporal Dementia (FTD) spectrum

Location: frontotemporal cortex
Predominant Proteinopathy: tau tangles (3R or 4R),
TDP43, FUS and pick bodies

Lewy Body dementia (LDB)

Location: frontotemporal cortex
Predominant Proteinopathy: Lewy bodies

Primary age-related tauopathy (PART)

Location: Limbic
Predominant Proteinopathy: Tau tangles (3R:4R)

Vascular dementia (VaD)

Location: blood vessles
Frequent pathology substrate: deposits of amyloid
aggregated (proteinopathy), or granular osmiophilic
material (GOM), or atherosclerosis,
leading to infarcts, ischemia and reduced
blood supply

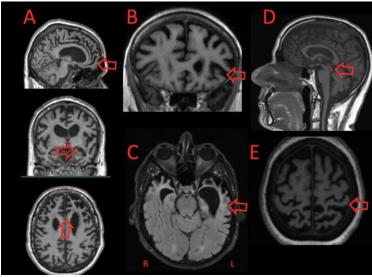


Dementia has an underlying cause



Blood tests and brain imaging to rule out reversible causes of dementia



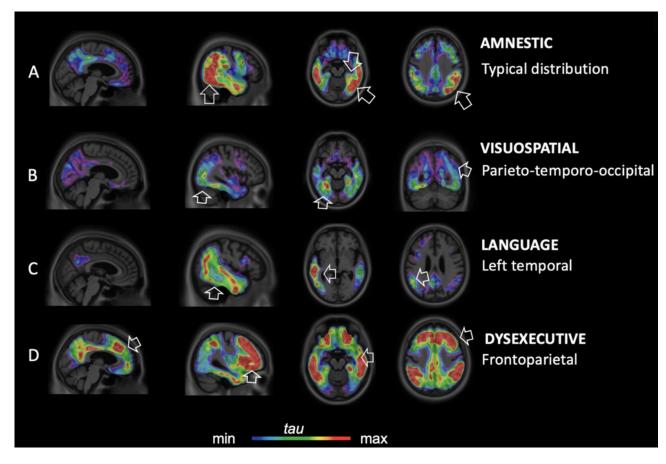




There are multiple forms of dementia



A single brain disease can present distinct dementia symptoms.





Dementia can also affect young people



Patients with young-onset dementia, including Down syndrome, require careful evaluation to rule out treatable causes of dementia among the many potential causes of dementia in that age group.

Biomarkers play a major role in ruling out Alzheimer's disease in young-onset dementia.



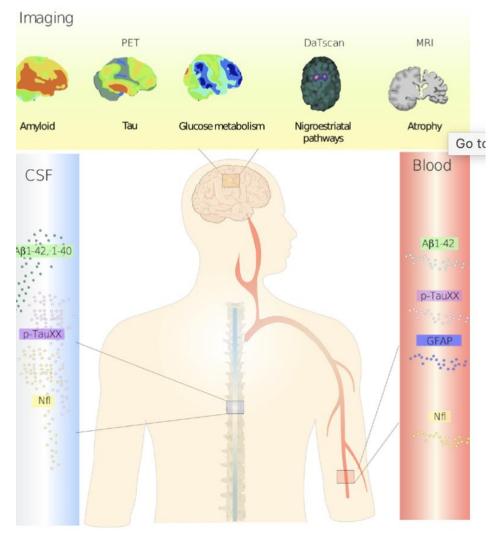




Biomarkers



Biomarkers provide opportunities for early diagnosis and disease-modifying interventions.

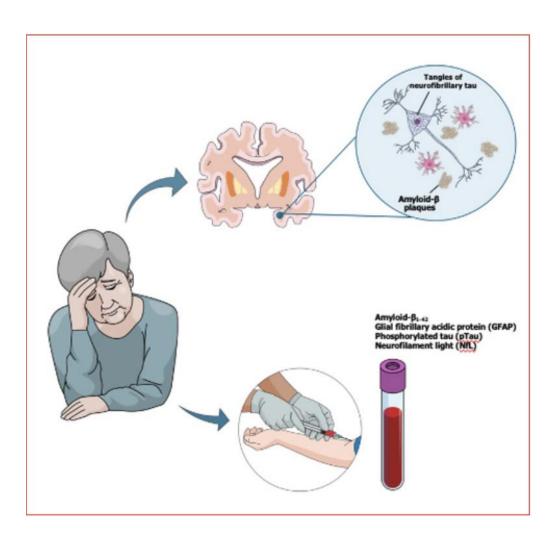




Biomarkers



Blood biomarkers brings the hope of affordable, accessible dementia diagnosis globally, including to low- and middle-income countries.





Professor José A. Morais





Professor José A. Morais

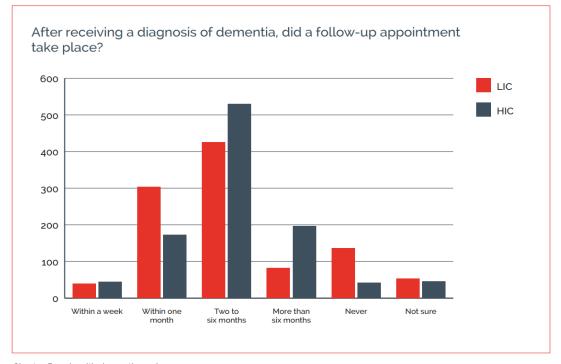
Director, Division of Geriatric Medicine
Academic Lead, Dementia Education Program
McGill University, Canada



The role of the clinician in disclosing a diagnosis



- The diagnosis of dementia is clinical.
- In complex situations, the clinician should say, "The diagnosis is not yet clear."
- Encourage the need for follow-up visits and additional complementary tests.





The challenges





In many countries, primary care physicians see several patients per hour, perhaps 6–10, and it is not possible to make an accurate dementia diagnosis in 10 minutes.

- Diagnosis is not 100% precise and co-pathologies are common.
- During initial assessment, it is important to rule out treatable causes of dementia.
- The physician's time is limited, thus additional healthcare professionals should contribute.



Gauging the patient's ability to receive the information





People experiencing cognitive decline tend to minimise their impairments.

- The problem of anosognosia, or "lack of awareness"
- To whom and how the diagnosis is made (e.g., person living with dementia, carer)
- Initially ask the person living with dementia and their carers what they want to know
- Dealing with a catastrophic reaction in response to the diagnosis



The physician's role in providing further information



- Discuss management of the condition.
- Provide information on stages of dementia.
- Discuss safety issues in the house and outdoors.
- Propose solving legal issues before the person loses capacity to decide.
- Refer the person living with dementia to associations and community resources.



Other aspects to cover



The clinician must ensure that the person living with dementia and their carers receive the best available care and support.



Among the many potential biases that can influence us as clinicians, there exist those inherent or underlying ones we carry that may significantly impact our diagnosis and treatment, namely our attitude towards such factors as sex, gender and ethnocultural differences.



Professor Suvarna Alladi





Professor Suvarna Alladi

National Institute of Mental Health and Neurosciences,

Bangalore, India

An Indian Perspective

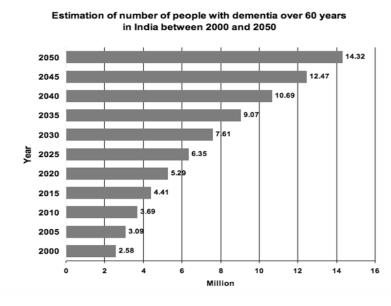
Dr Suvarna Alladi, Prof of Neurology, National Institute of Mental Health and Neurosciences (NIMHANS),
President, Alzheimer's and Related Disorders Society of India (ARDSI) Hyderabad Chapter

Jayeeta Rajagopalan, Early Career Researcher (ECR), Strengthening Responses to Dementia in Developing Countries,
National Institute of Mental Health and Neurosciences (NIMHANS)

Early diagnosis of dementia: A complex problem requiring a multidimensional approach for India

"Much of the increase will take place in low and middle income countries. In 2015, 58% of all people with dementia live in LMICs rising to 68% in 2050 "

Demographic transition





Low and middle income countries

High income countries

Number of people with dementia in low and middle income countries

compared to high income countries

Millions of people with

2015

Early diagnosis of dementia: A complex problem requiring a multidimensional approach for India

Dementia Diagnosis in India

- Low awareness and stigma associated with dementia delaying diagnosis.
- Lack of sufficient dementia specialized professionals.
- Diversity in socioeconomic factors impacting access to health care services.
- Linguistic diversity: few culturally validated cognitive tests available.
- Around 100 memory clinics across the country.
- Out of pocket expenditures accounting for majority of Total Health Expenditures
- COVID-19 pandemic has further complicated dementia diagnosis. While telemedicine initiatives were started, difficulties in conducting cognitive tests via virtual platforms remain.

Heterogeneity in health seeking behaviors as a result of **diversity in** socioeconomic, cultural and demographic factors affect whether persons with dementia receive any diagnosis at all

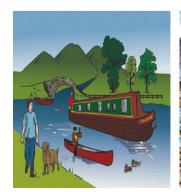
Early diagnosis of dementia: A complex problem requiring a multidimensional approach for India

Linguistic, Cultural and Educational Diversity

Considering the linguistic diversity in India with 122 major languages and 1599 other languages being spoken, the Indian Council of Medical Research developed Neuro Cognitive Tool-Box (ICMR-NCTB) for diagnosis of dementia in 5 Indian languages: Hindi, Bengali, Telugu, Kannada, Malayalam.

Journal of the International Neuropsychological Society (2019), 1-15
Copyright © INS. Published by Cambridge University Press, 2019.
doi:10.1017/S1355617719001127

Standardising Dementia Diagnosis Across Linguistic and Educational Diversity: Study Design of the Indian Council of Medical Research-Neurocognitive Tool Box (ICMR-NCTB)







Gowri K. Iyer^{1,2}, Avanthi Paplikar³, Suvarna Alladi^{1,3,*} , Aparna Dutt^{4,5}, Meenakshi Sharma⁶, Shailaja Mekala^{1,7}, Subhash Kaul^{1,8}, Aralikatte Onkarappa Saroja⁹, Gollahalli Divyaraj¹, Ratnavalli Ellajosyula¹⁰, Amitabha Ghosh⁴, Roopa Hooda¹¹, Sunita Justus¹², Rajmohan Kandukuri¹, Arfa Banu Khan⁹, Robert Mathew¹³, P.S. Mathuranath^{3,12}, Ramsekhar Menon¹², Ranita Nandi⁴, Jwala Narayanan¹⁰, Ashima Nehra¹¹, M.V Padma¹¹, Apoorva Pauranik¹⁴, Subasree Ramakrishnan³, Prerana Sabnis^{10,15}, Lekha Sarath¹², Urvashi Shah¹⁶, Manjari Tripathi¹¹, P.N. Sylaja¹², Ravi Prasad Varma¹², Mansi Verma¹¹, Feba Varghese³: ICMR Neurocognitive Tool Box Consortium

Iyer, Alladi et al., 2019, Journal of International Neuropsychological Society Paplikar, Alladi et al., 2020, Annals of Indian Academy of Neurology Paplikar, Alladi, et al., 2021 Archives of Clinical Neuropsychology

Ayushman Bharat



India

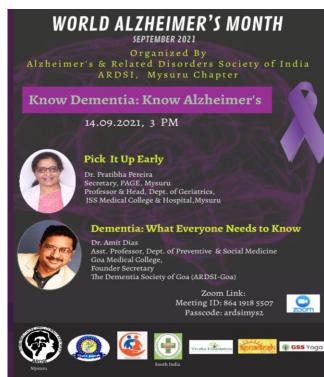
- Total No. Of Health And Wellness
 Centres(HWC)
 - 76,663

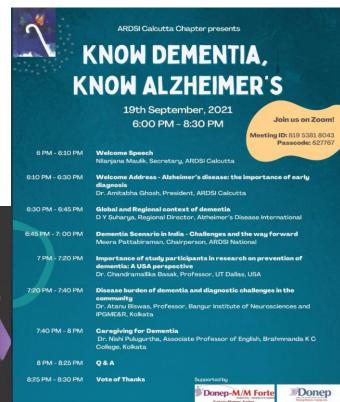
- Two-pronged approach
- Public health insurance scheme that provides families a coverage of up to 5 lakh per year for secondary and tertiary hospitalization for the socioeconomically disadvantaged groups.
- The Government is transforming existing primary health care infrastructure into health and wellness centers with the aim of providing comprehensive primary care.
- A total 150,000 HWCs to be set up by December 2022
- A step towards universal health coverage

Early diagnosis of dementia: A complex problem requiring a multidimensional approach for India

Key Takeaways

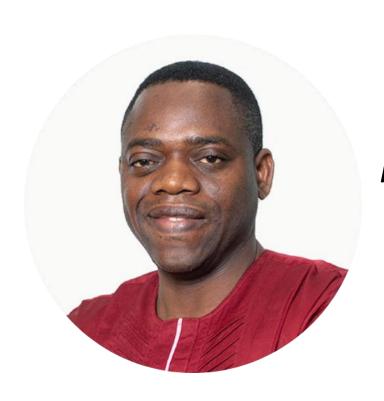
- Dementia diagnosis is complex influenced by a wide range of factors in the Indian setting.
- Strategies that take into account the diversity and limited resources available are urgently needed.
- Crucial that persons with dementia and their families are placed at the centre of these efforts.
- Increasing awareness about symptoms will be crucial to improving diagnosis rates.
- As a part of this years World Alzheimer's month theme
 'Know Dementia, Know Alzheimer's', multiple activities
 are being conducted to raise awareness among the
 general public as well as health care professionals such
 as talks, webinars and memory cafe.





Dr. Rufus Akinyemi





Dr. Rufus Akinyemi

Neuroscience and Ageing Research Unit, Institute for Advanced Medical Research and Training, College of Medicine,

University of Ibadan, NIGERIA









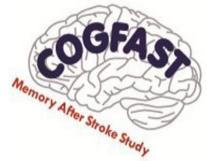


The challenges of diagnosing dementia in Africa

Rufus O. Akinyemi MBBS, MSc, PhD, MWACP, FMCP, FGBHI.

Deputy Director, Centre for Genomic and Precision Medicine Senior Research Fellow, Neuroscience and Ageing Research Unit, IAMRAT College of Medicine, University of Ibadan, Nigeria. Consultant Neurologist, Dept of Medicine, University College Hospital, Ibadan, Nigeria.



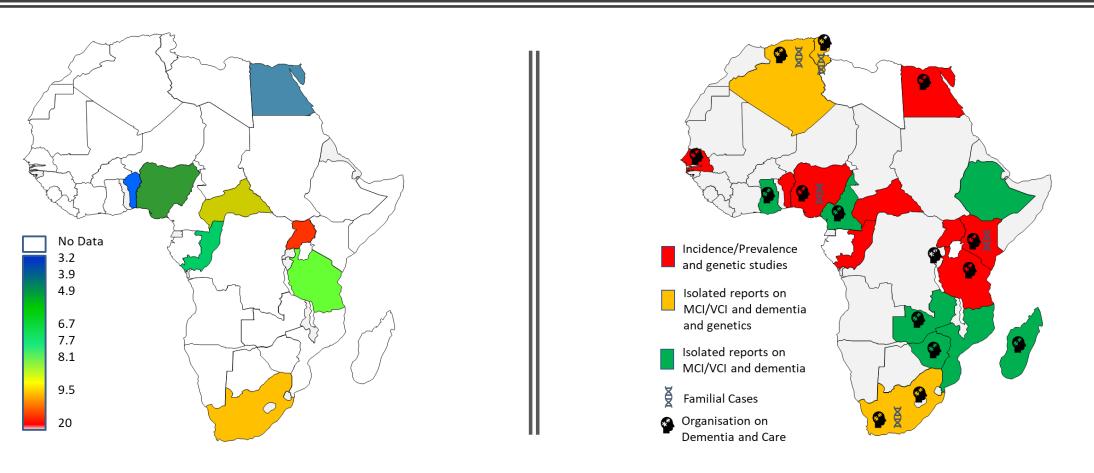








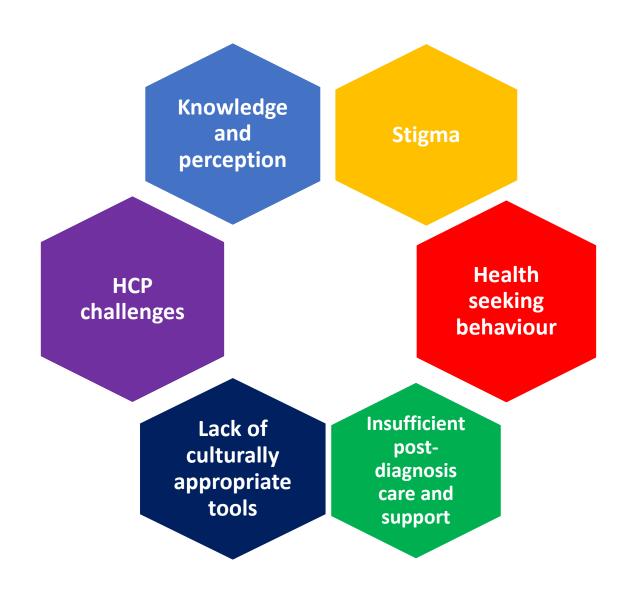
Variation in prevalence estimates of dementia in Africa



Akinyemi et al, Alzheimer's and Dementia, 2021



The Challenges



The Future: African Dementia Consortium

Africa-led international dementia consortium for research and care

Deep phenotypic, genetic and sociodemographic, imaging and multiomics database

Set up an online portal and bio-banking system for data sharing and collaboration

Capacity building and educational framework to support training including dementia diagnosis

Develop stakeholders platform

Promote translational research

Dementia ELSI



Claire Webster





Claire Webster

Founder and Ambassador, Dementia Education Program, McGill University / Founder and President of Caregiver Crosswalk Inc.

McGill University, Canada



My Journey Has Led Me Here...

"Good luck,
Mrs. Webster!"



"I deeply believe that if I had been properly educated upon my mother's diagnosis and told that I would need support, I would have been a better caregiver to my mother. I was frustrated and did not understand her behaviour."

Claire Webster, Certified Dementia Care Consultant

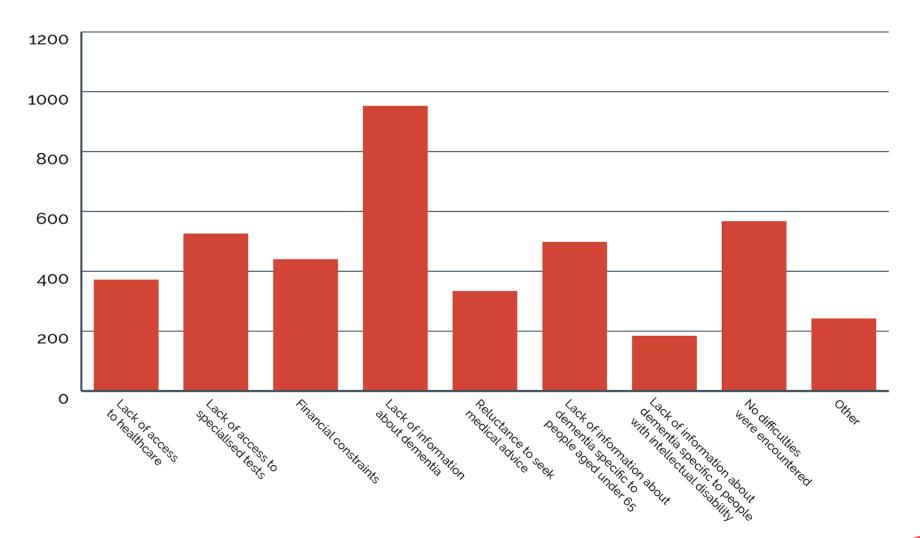




A lack of education about a dementia diagnosis will have a significant impact on the quality of care as well as safety of the individual and their carer(s).



What difficulties were encountered as part of receiving the diagnosis of dementia?



























If these signs are new, they may be a sign of dementia.

Dementia is not a normal part of ageing.

Speak to your doctor or contact your dementia and Alzheimer association.



Navigating the Journey of Dementia After a Diagnosis A Prescription of Education and Support



Accept

Educate

Plan Ahead

Navigate

Advocate



Understanding the impact of COVID-19 on people with dementia and their carers

Chapter 21



World Alzheimer **Report 2022:** Post Diagnostic Management & Support -A Prescription of Care

- A natural history of dementia and stage specific general management – pharmacological and nonpharmacological approaches.
- Impact of dementia on the care partner(s) including young carers.
- Caregiving customs and challenges among diverse cultures.
- An analysis of the curriculum of medical and allied healthcare professions around the world in post-diagnostic management and support from a person/patient centered approach, as well as best practices.
- Latest research in preventing cognitive decline.
- Government strategies and policies to support persons living with dementia and care partners.



Questions





@AlzDisInt
#ADIwebinar

Closing remarks





Paola Barbarino CEO,

Alzheimer's Disease International (ADI)

@AlzDisInt

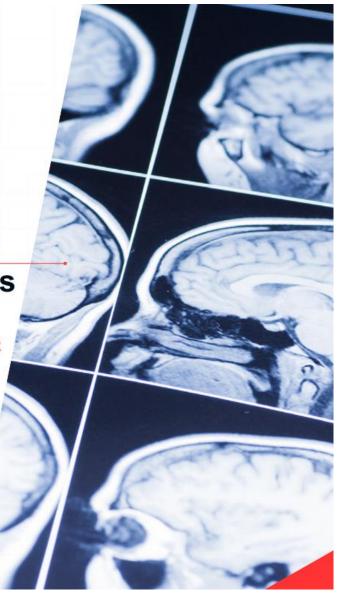


WEBINAR

Innovations in diagnosis and diagnostics

A WORLD ALZHEIMER REPORT 2021 WEBINAR

Tuesday 19 October 1pm London | 8am New York



Register at https://bit.ly/3EYmESe



THANK YOU.

Follow ADI on Twitter and Instagram @AlzDisInt | Like us on Facebook <u>/alzdisnt</u>

Visit our website: www.alzint.org