

# Leveraging Collaborations and Technology for the Dementia Care Gap in LMICs

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Dean's Grand Rounds RCPsych

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# Disclosure slide

- I have nothing to disclose



**Dean's  
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# Outline

- Introduction
- Overview of burden/ gaps
- Existing health care patterns
- Evidence based interventions
- Barriers
- Future directions

# Overview- Burden of Dementia

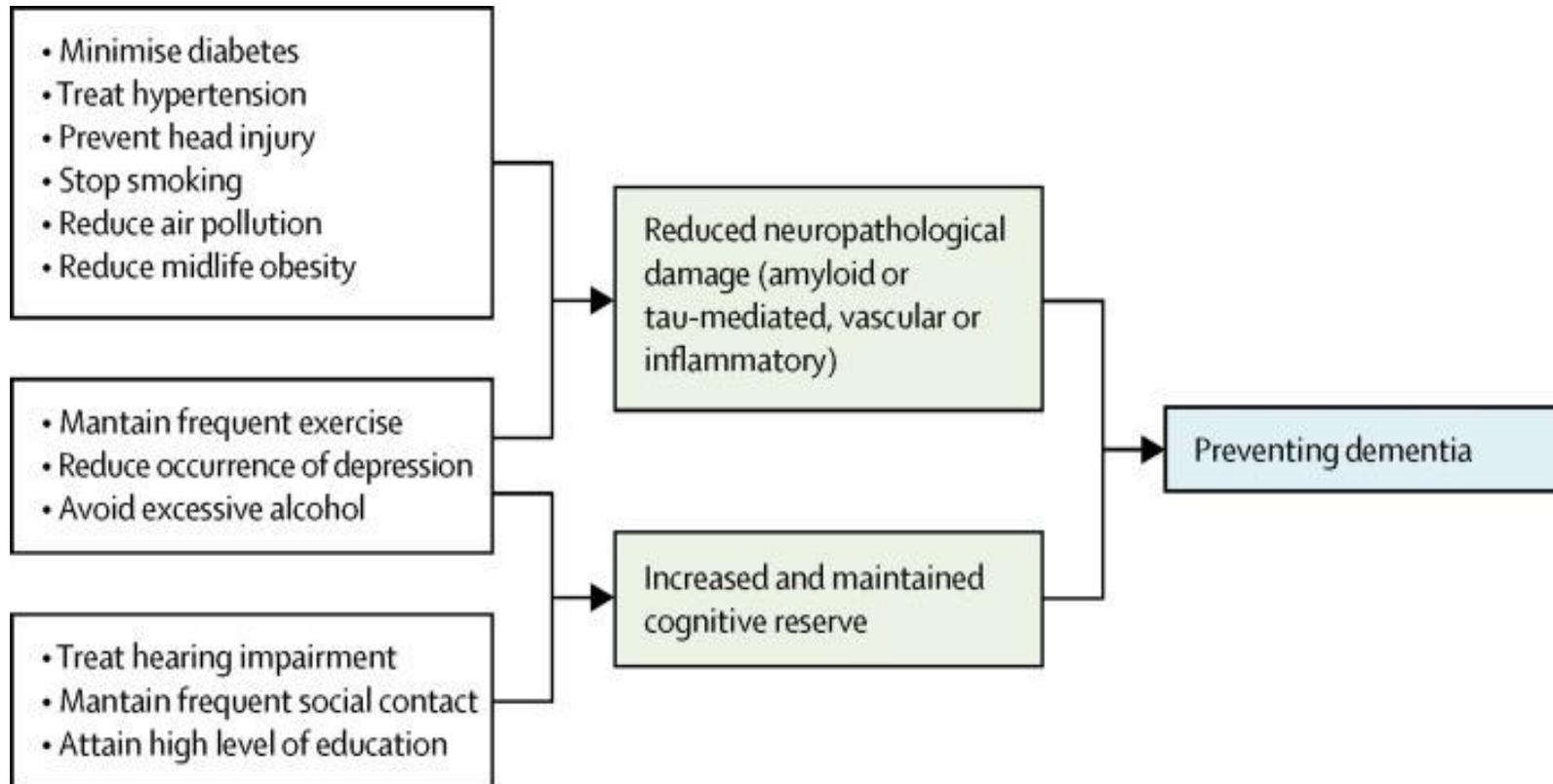
- Increasing burden of dementia worldwide
- Dementia is higher in low-income and middle-income countries (LMICs)
- Rapid demographic transition and population growth in LMICs compared to HICs
- About 2/3 of people with dementia globally reside in LMICs
- Guidelines and policies for dementia care are largely unavailable or poorly/ partly implemented in most LMICs
- Limited resources available for the increasing burden
- Inequitable access to diagnosis and care
- Poorly coordinated health care pathways/ dearth of training/ Late presentation
- The family (females) bears the burden of care in most LMICs especially in sub-Saharan Africa (sSA)

\*LMICs (Low-income and middle-income countries) \*HICs (High-income-countries)

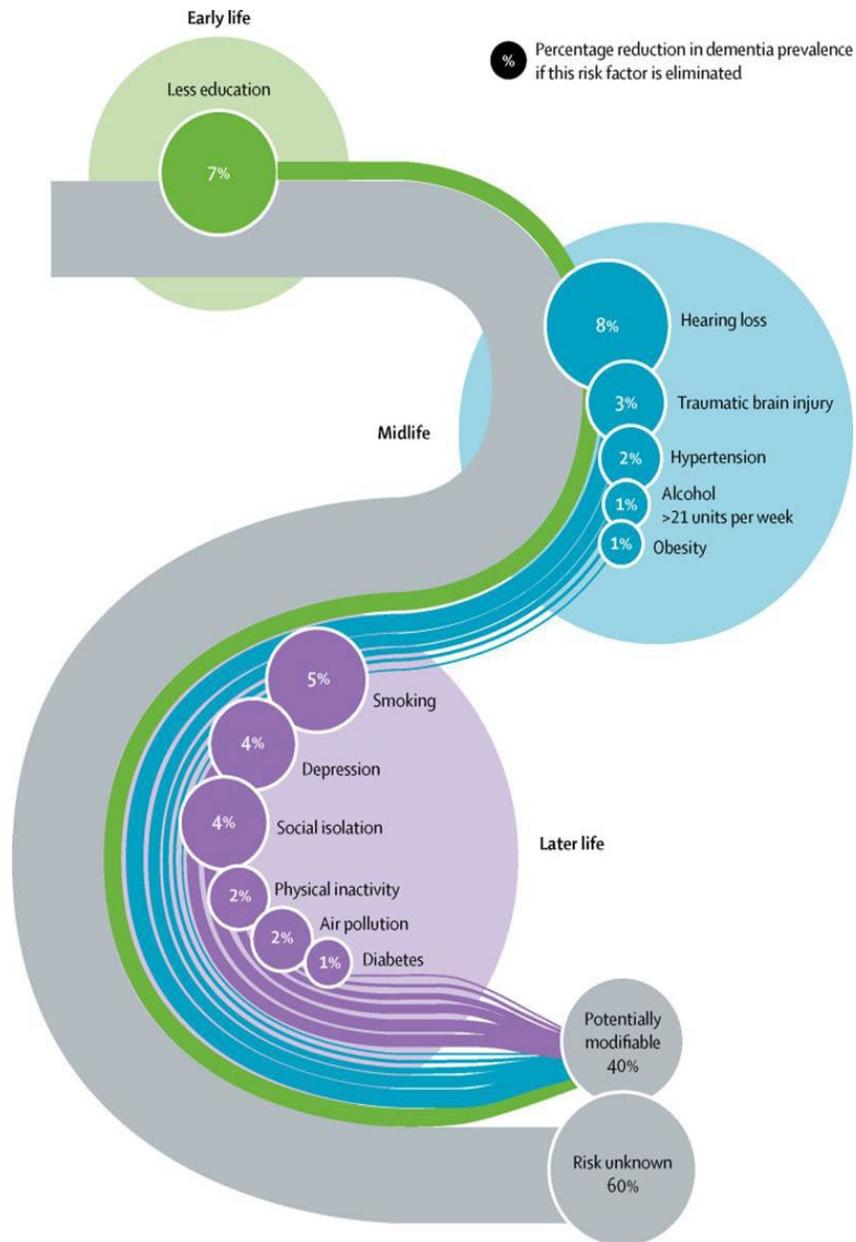
# Overview- Care gaps

- Transverse resources (personnel, funds), treatment, and research
- Lack of relatively accurate estimates for the treatment gap for dementia in LMICs
- Estimated to be between 80%-90% in most LMICs countries e.g (Nigeria, India, Somaliland, etc.)
- Identifying the gaps helps to tailor interventions
- Primary care is pivotal in reducing the dementia care gap
- Evidence from HICs and some LMICs show decrease in prevalence addressing it at primary level of care
- Prevention potential of dementia is estimated to be over 40-50% in LMICs
- Essential to tackle modifiable risk factors

## 12 modifiable risk factors as proposed by Livingstone et al. (2020)



- Livingstone, Gill et al. "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission." *Lancet (London, England)* vol. 396,10248 (2020): 413-446. doi:10.1016/S0140-6736(20)30367-6



	Relative risk for dementia (95% CI)	Risk factor prevalence	Community	Unweighted PAF	Weighted PAF*
<b>Early life (&lt;45 years)</b>					
Less education	1.6 (1.3–2.0)	40.0%	61.2%	19.4%	7.1%
<b>Midlife (age 45–65 years)</b>					
Hearing loss	1.9 (1.4–2.7)	31.7%	45.6%	22.2%	8.2%
Traumatic brain injury	1.8 (1.5–2.2)	12.1%	55.2%	9.2%	3.4%
Hypertension	1.6 (1.2–2.2)	8.9%	68.3%	5.1%	1.9%
Alcohol (>21 units/week)	1.2 (1.1–1.3)	11.8%	73.3%	2.1%	0.8%
Obesity (body-mass index $\geq 30$ )	1.6 (1.3–1.9)	3.4%	58.5%	2.0%	0.7%
<b>Later life (age &gt;65 years)</b>					
Smoking	1.6 (1.2–2.2)	27.4%	62.3%	14.1%	5.2%
Depression	1.9 (1.6–2.3)	13.2%	69.8%	10.6%	3.9%
Social isolation	1.6 (1.3–1.9)	11.0%	28.1%	4.2%	3.5%
Physical inactivity	1.4 (1.2–1.7)	17.7%	55.2%	9.6%	1.6%
Diabetes	1.5 (1.3–1.8)	6.4%	71.4%	3.1%	1.1%
Air pollution	1.1 (1.1–1.1)	75.0%	13.3%	6.3%	2.3%

Data are relative risk (95% CI) or %. Overall weighted PAF=39.7%. PAF=population attributable fraction. Weighted PAF is the relative contribution of each risk factor to the overall PAF when adjusted for communality.

Table 1: PAF for 12 dementia risk factors

Fig. 7- updated life-course model of potentially modifiable risk factors for dementia, including the three new risk factors. Livingston, Gill et al. "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission." *Lancet (London, England)* vol. 396,10248 (2020): 413-446. doi:10.1016/S0140-6736(20)30367-6



# Existing health care patterns

- What are the health care patterns for dementia care?
- The family is the bedrock of dementia care in most LMICs (sSA)
- Dementia care is primarily by family members
- Diagnosis was considered the purview of psychiatrists and neurologists
- The pathway to care is usually tortuous

# Where are we now in addressing the dementia care gap? Do we reinvent the wheel ?

- Interrelationship of family dynamics and their communities
- integrated memory care, MIND at home (maximizing interdependence)
- Home management/ Community care model
- Collaborations and community-based care
- Technology (post COVID-19 pandemic)
- Advancements in preventive, therapeutic and rehabilitative domains
- Varying levels across the 132 LMICs, some more than others
- Case study- Nigeria and Pakistan/*India/Bangladesh*





# Evidence based interventions- Collaborations (Nigeria)

## ❖ Community focused collaborations

- Community health workers
- Faith based organisations
- Non-Governmental / Governmental Organisations

*Alzheimer's Disease Association of Nigeria ADAN*

*National Senior Citizen Centre NSCC*

- Volunteers

## ❖ Research focused collaborations

- The African Dementia Consortium



**Confidence Aged Care Home**

**CACH**  
IT'S THURSDAY:  
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# Current practice

- Transition from basic advocacy to dedicated dementia awareness (*The WHO 2017-2025 public health dementia plan*)
- Population awareness, primary prevention, and lifestyle modifications (*early identification, blood pressure control, exercise, diet, alcohol/ nicotine reduction etc.*)
- Pharmacologic and non-pharmacologic approaches-Cognitive stimulation therapy
- Training/ Task shifting strategies
- **Multidisciplinary approach**- involvement of other physicians, non specialist health workers, volunteers, civil societies, religious and community leaders etc.
- Support services memory groups, respite care, day-care centers, and community-based social activities
- Research on dementia –biomarkers, genetic and epigenetic markers
- Use of culturally appropriate tool (The IDEA Study Screening Instrument )

# Collaborations for dementia care- Nigeria contd.

## ❖ Research focused collaborations

- The Ibadan Indianapolis dementia project- Prospective community survey
- The Ibadan Study on Aging- population based follow up survey
- The African Dementia Consortium (Community Engagement across the African Dementia Consortium (AfDC) Sites)
- READD - *The Recruitment and Retention for Alzheimer's Disease Diversity Cohorts in the Alzheimer's Disease Sequencing Project (READD-ADSP)*
- *First-ever large-scale, case - control genetic epidemiological study involving PLWD and disease - free apparently healthy control*
- *Create a critical resource of diverse ancestral groups (previously underrepresented in genomics research) for genetic studies of Alzheimer Disease*
- The Origin of Alzheimer's Dementia- *Understand genetic, ancestral and clinical features of AD in AA, community engagement*

**Preparation for tea-word list item (Question 5)**  
I am going to read out a list of words. Please listen carefully and I will ask you to repeat them back to me once I have finished (read out the words slowly).

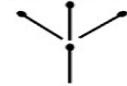
**First attempt:** Now tell me all the words you can remember (tick on the grid the words remembered)

**Second attempt:** Now I will read out the words again, listen carefully and I will ask you to repeat as many as you can. Now tell me all the words you can remember (tick on the grid the words remembered)

**Third attempt:** Now I will read out the words one last time, listen carefully and I will ask you to repeat as many as you can. Now tell me all the words you can remember (tick on the grid the words remembered).

	First attempt	Second attempt	Third attempt
Subst			
Verb			
Letter			
Queen			
Ticket			
Grass			
Corner			
Stone			
Book			
Sink			
1.	I will tell you the name of something and I want you to describe what it is. What is a bridge? (correct answer: something that goes across a river, canyon 2 if road or road)	0 if incorrect 2 if correct	Score: ___/2
2.	I want you to name as many different animals as you can in one minute.	Number of animals named: ___ 0 for 0-3 animals named 1 for 4-7 animals named 2 for 8 or more animals named	Score: ___/2
3.	Who is the chief/head/leader of this village?	0 if incorrect 1 if correct	Score: ___/1
4.	What day of the week is it?	0 if incorrect 2 if correct	Score: ___/2
5.	Can you tell me the ten words we learned earlier? Try to remember as many as you can.	0 for no words remembered 1 for 1 word 2 for 2 words 3 for 3 words 4 for 4 words 5 for 5 or more words	Score: ___/5
6.	Can you make the design shown below using these four matchsticks. I will show you once and then you have to copy exactly	Score 1 for each part of the design that is performed correctly 1. Middle two matchstick heads pointing same way 2. Outside two matchsticks pointing at an angle 3. Matchstick heads are reoriented correctly	Total number of points: ___/3

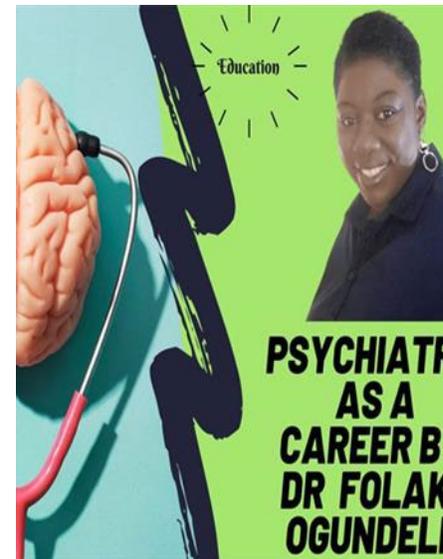
The examiner should make the design first using the matchsticks and specifically point out to the person that the heads of the matchsticks all need to point the same way. Once the examiner has made the shape, collect up the matchsticks and place them in front of the person being interviewed.



Total Score: \_\_\_/15

# Technology / Telepsychiatry

- Patient management / Caregiver support
  - Awareness/Counselling
  - Lifestyle management
  - Patient monitoring and security
  - Training/ Education
  - *Phone, Apps, Virtual assistance, Virtual communication platforms etc.*
- ❖ SENSE-Cog Asia/ Europe



 International Psychogeriatric Association  
Better Mental Health for Older People

## Advocacy and Resources

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### Older adults and virtual mental health

**LEAVING THEM BEHIND: OLDER ADULTS AND MENTAL HEALTH CARE IN THE ERA OF COVID · EXPERIENCES FROM A NIGERIAN HOSPITAL**

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**INTRODUCTION**

# Evidence based interventions- Asia

- **SENSE-Cog Asia: A Feasibility Study of a Hearing Intervention to Improve Outcomes in People With Dementia**
- Evidence-based
- Non-pharmacological interventions adapted to improve dementia-related outcome
- An adapted hearing support intervention- full assessment of hearing function, fitting of hearing aids, and home-based support from a “hearing support practitioner”
- Carried out in 3 phases- Phase 1 done in Pakistan, India, and Bangladesh
- Intervention was feasible and acceptable
- Improved quality of life in PLWD and BPSD/ Reduction in care burden
- Promising outcome but further studies recommended
- **Others**
- *STRiDE*
- *LatAm-FINGERS*



# Challenges

- Cultural and religious beliefs
- Stigma
- Erosion of key informal care systems
- Unavailability resources
- Insufficient funds/ Out of pocket expenditure
- Inadequate/ depleting manpower/Apathy
- Rapid socio-economic transitions
- Globalisation/ Urbanisation
- Scanty research/ Siloed research
- Absent/ poor legislation and policies

# Overview of challenges faced

Target areas	HICs	LMICs
<i>Knowledge/perception</i>	Age related problem Cognitive decline	Poor awareness Supernatural causes Memory loss/Age related
<i>Personnel/ Funds/ Infrastructure</i>	Available infrastructure Insufficient personnel	Grossly inadequate personnel and economic capital Inadequate training/ apathy/ Disinterest in sub-specialty Absent or inadequate infrastructure
Stigma	Low	High Witchcraft Punishment for misdemeanours Caregivers stigmatized
<i>Diagnosis</i>	About 75% PWD are underdiagnosed globally	Dementia diagnosis is less than 10% ? Appropriate testing tools Ill defined pathways
<i>Treatment/ Management</i>	Consideration of medicolegal issues/ end of life issue Care giver support Available medications and investigations	Pharmacological/ dilemma of shared care Psychotherapy/Co-morbidities Poor care giver support Medicolegal / End of life issues
Research	Most from HICs	Still scanty
Guidelines/ policies	Most	Few/ None

# Future directions

- Target modifiable risk factors
- Task shifting/ Incentivise personnel
- Support responsive health systems
- Incorporate dementia (psychiatric) care into primary healthcare
- Merging dementia care with management of other chronic medical/ psychiatric conditions
- Support equity in access to dementia prevention, diagnosis, treatment and care
- Establishment and implementation of guidelines and policies
- Adoption of the GAP-Dementia by WHO
- Achieve the WHO Global Plan of Action on Dementia's target of diagnosing at least 50% of PLWD in 50 countries by 2025
- Effective funding mechanisms/ collaborations for research and public health interventions

# ~~Conclusion~~

## Perspectives

- Identifying these gaps guides tailored interventions that addresses the health needs of PLWD
- The family is the bedrock of dementia care in most LMICs
- Culturally considerate innovations that are patient centric, yet evidence based
- Improve the quality-of-life of PLWD and their caregivers/ families
- Leverage collaborations and community-based services for prevention, early detection, diagnosis and post diagnostic care



*Thank You*

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