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COMMITTEE ON FOREIGN AFFAIRS

Subcommittee on Africa, Global Health, Global Human Rights and International Organizations

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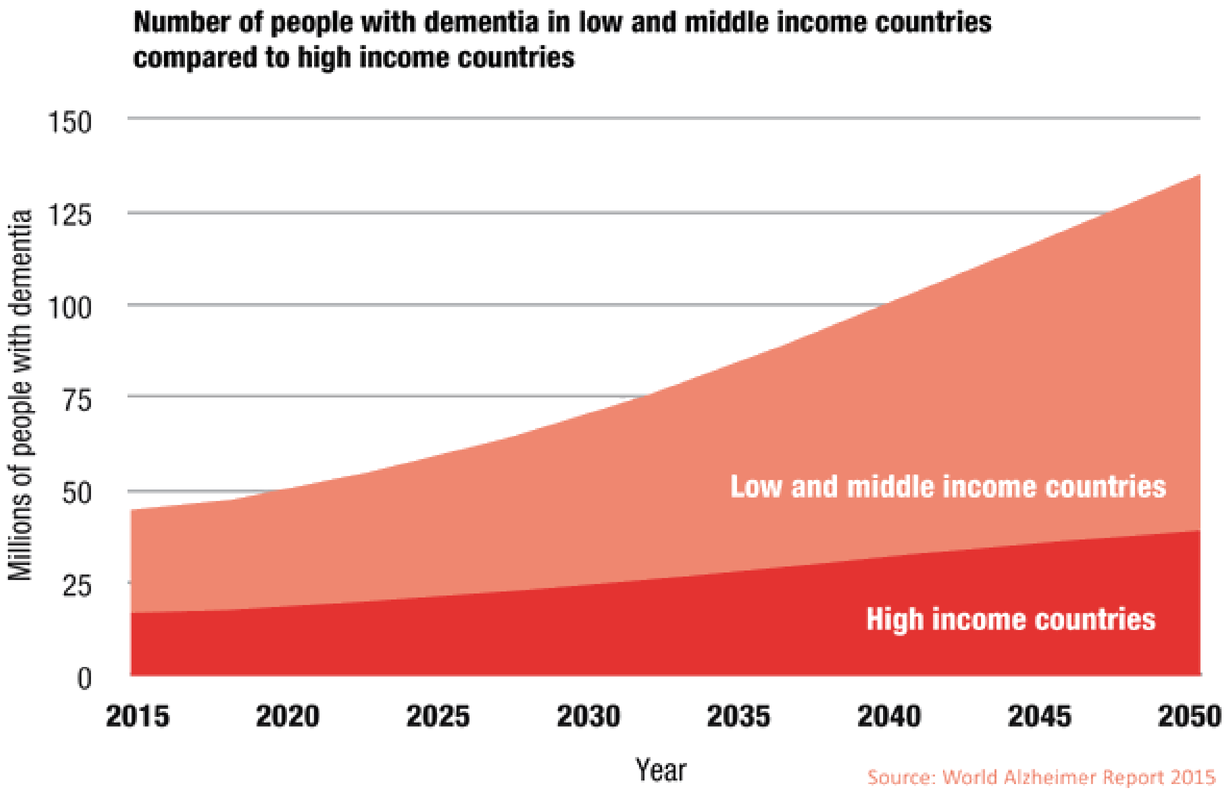
"A Global Update on Alzheimer's Disease"

Thank you for the opportunity to appear before the subcommittee today and offer a global view update on dementia. I have been working with persons with Alzheimer's disease and related disorders and their families since 1986. Since 2011 our consultancy has served as policy and advocacy advisers to Alzheimer's Disease International (www.alz.co.uk) the umbrella organization of over 90 national Alzheimer associations around the world, including the US Alzheimer's Association (www.alz.org).

It is worth noting that the US Association and ADI share a common founder--the late Jerome Stone-thus there was some sense of dementia being more than a domestic issue was present in the early 1980's even as we saw initial organizing around the problem.

Our work with ADI has put my associate Kate Gordon and I in the middle of a burst of international energy and work streams that are moving the issue of dementia closer to the public health priority experts believe it needs to be. My plan with my limited time today is first review a few key facts and then highlight on key developments that other witnesses have not covered.

The facts are stark. Globally 47.5 million people live with some form of irreversible dementia, (https://www.alz.co.uk/research/world-report-2015) a number that will grow to 130 million by 2050 with most of the new cases and burden of disease falling on lower and middle income ountries. Global cost of AD is estimated at just above 1% of global GDP ($818 billion USD)



Number of people with dementia in low and middle income countries compared to high income countries

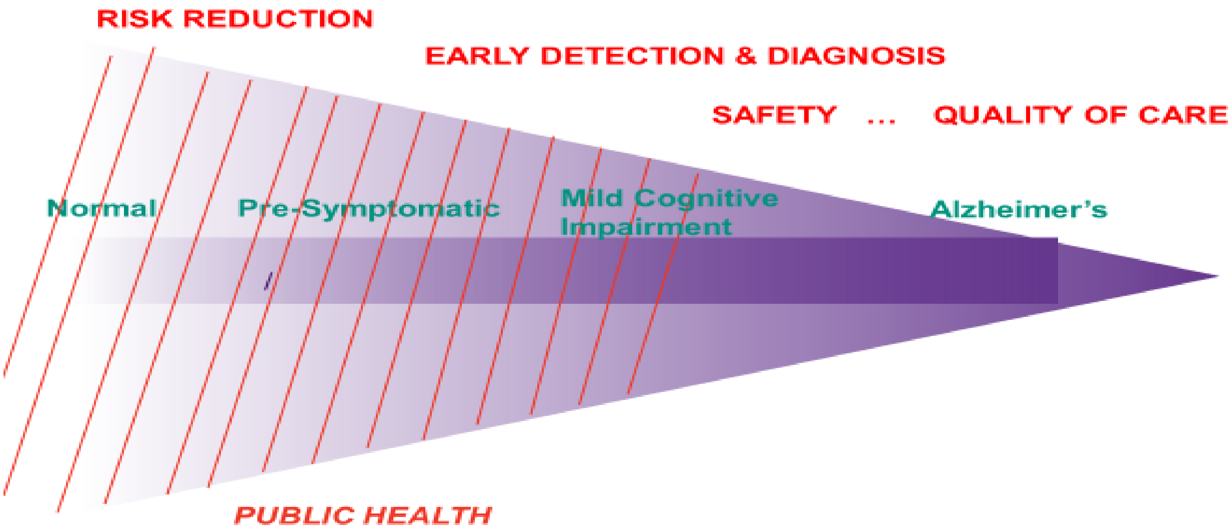
Source: World Alzheimer Report 2015

Of possible special interest to this subcommittee has been the publication of a report on AD in Sub Saharan Africa (https://www.alz.co.uk/research/dementia-sub-saharan-africa.pdf) which estimates 2.13 million persons with dementia now live in the region, a number that is expected to roughly double every 20 years.

Let me now review seven key global developments.

1. **Dementia is increasingly understood to be a life course disease by key policy-makers, not merely a disease of older persons.** Population aging is driving the numbers but slowly the general public perception of dementia that it must necessarily be an older person quite disabled in the latter stages of the disease is changing, as some persons diagnosed early in the disease have put a different face on what it means to live with dementia. Perceptions are also changing in countries rich in scientific resources we can image changes in the brain before symptoms develop, and anywhere in the world we can begin to use the tools of public health to reduce population risk of dementia in late life.

   True, awareness raising activities have a more complicated story to tell with a 30 year disease process to describe as illustrated below, and everywhere in the world there is constant messaging needed that dementia is not a normal part of aging, but the life course view is taking hold increasingly in policy circles.



RISK REDUCTION

EARLY DETECTION & DIAGNOSIS

SAFETY ... QUALITY OF CARE

Normal

Pre-Symptomatic

Mild Cognitive Impairment

Alzheimer’s

PUBLIC HEALTH

2. **Detection and diagnosis are a stubborn problem everywhere**. Research shows that most people currently living with dementia have not received a formal diagnosis. In high income countries, only 20-50% of dementia cases are recognized and documented in primary care. This ‘treatment gap’ is certainly much greater in low and middle income countries. Without **a diagnosis**, there can’t be treatment, care and organized support or opportunity to volunteer for clinical research. This gap should be of interest to health systems as persons with impaired thinking and other chronic disease are expensive and have difficult lives navigating complex health decisions and treatment regimens and are frequently only seen in deep crisis.

   United States figures suggest that only about 50% get a formal diagnosis, and more troubling is the fact that as many as 30% or persons with a diagnosis in their medical record have not been informed of their diagnosis.

3. **In the Americas, in 2015 PAHO/OPS adopted a regional dementia action plan and in 2017 the World Health Assembly adopted a global dementia action plan.**

   Taking a right based approach, these action plans call on and will provide technical support for national government plans and policies over the next 5 years to take advantage of this newer understanding of dementia and to plan response across the spectrum of disease.

   30 countries have published national plans, but I would note that only one country has taken serious action on dementia without a strong civil society push. (with its deeper and more personal knowledge of the issues and its advocacy capacity.)

   On rights let me note that persons with ADRD are in some cases using the Convention on Rights of Persons with Disabilities as a platform for action on care and support and that dementia has been a special issue in the OAS regional convention on the Rights of Older Persons (now out for ratification) a regional declaration on older persons rights by the African Union and a major topic in the ongoing work of the UN Open Ended Working Group on Aging and its special rapporteur.

4. **A broader community of interest in dementia as a social issue is emerging.**

   This is taking many forms, such as social media awareness raising and organizing by young students and workers in Indonesia, myriad dementia friendly community programs unique to place and culture or dementia being an agenda item at the World Economic Forum in Davos or as it is this week at the Salzburg Global Seminar. In the wake of the Japanese tsunamis, natural disaster authorities have begun better planning for persons with dementia in those circumstances. Multiple international NGO’s help raise awareness during World Alzheimer’s Month (https://www.worldalzmonth.org) Even Pope Francis made a major address on World Alzheimer’s Day!

5. **Dementia is gaining recognition in the non-communicable disease movement**.

   Beginning with the UN Political Summit and Declaration on NCD's in 2011 through the present moment, dementia issues have been raised in two ways-from a public health perspective dealing with shared risk factors for NCD's in late life with brain health messaging integrated into a smoking cessation campaign and from the perspective of the challenges of self-managing chronic disease when one is seriously cognitively impaired. It is important to note that this is promising but that the community has yet to see the declaration intent on dementia implemented in NCD plans generally.

6. **(Some) political leadership has embraced action on dementia (some of the time)**.

   In December 2013 the G-8 (now G-7) held a major summit https://www.gov.uk/government/publications/g8-dementia-summit-agreement and then convened several follow on high level meetings and activities that set in motion action to increase commitments to government backed research funding and greater international cooperation on science and policy, including care policy. Of special note is the stimulus to the Organization for Economic Co-operation and Development (OECD) to consider what changes could be made to promote and accelerate discovery and research **and** the transformation of innovative and efficient care and services. The subsequent formation of a World Dementia Council https://worlddementiacouncil.org/ which has been an advocate for innovative and global finance models, integrated drug development and the encouragement of open science collaborative research, including big data.

7. **Myriad strong scientific meetings and cooperation are now the norm.**

   The world's largest scientific meeting on Alzheimer's is the Alzheimer's Association International Conference (https://www.alz.org/aaic/) to be held this July in Chicago, followed immediately by the annual conference of Alzheimer's Disease International (https://www.alz.co.uk/ADI-conference) Dozens of smaller regional and specialty meetings are harnessing scientific interest, opening new theories of the disease and supporting thousands of active scientists, especially younger professionals.