The Burden of Alzheimer's Disease and Related Diseases in Vulnerable Populations

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What is Alzheimer's disease (AD?)

- AD is a degenerative brain disease and the most common cause of dementia, accounting for approximately 70% of patients.

- Dementia is not a specific disease but rather an overall term that describes a group of symptoms.
World Health Organization projections

• In 2025, about 3/4 of the estimated 1.2 billion people over 60 years old will reside in developing countries.

• By 2040, if there are no changes in mortality or burden-reduction in dementia, 71% of 81.1 million people with dementia will be living in the developing world.
Figure 2.4
The growth in numbers of people with dementia (millions) in high income (HIC) and low and middle income countries (LMIC)

Source: Alzheimer's Disease International
"If we aren’t intersectional, some of us, the most vulnerable, are going to fall through the cracks."

- Kimberle Williams Crenshaw
  (civil rights advocate)
What is the prevalence of dementia in vulnerable populations?

Photo: Alex Kornhuber
Important disclaimer:

- It is estimated that 5 to 7% of people throughout the world live with dementia;

- However, the lack of standardized diagnostic procedures throughout the world is a major limitation in the estimation of the true burden of dementia.
Dementia in indigenous populations

- There is no universally-accepted definition of what constitutes an "indigenous population".
- Self - identity
- It is estimated that 370 million people worldwide - 5% of the world population - consider themselves indigenous.
- There are only 15 studies looking at the impact of dementia in indigenous populations.
• It is estimated that 370 million people worldwide - 5% of the world population - consider themselves indigenous.

• There are only 15 studies looking at the impact of dementia in indigenous populations.

  - These studies suggest that the prevalence of dementia doubles with every 5.5-year increase in age after age 60.

  - Estimates of prevalence dementia in indigenous populations ranged widely, from 0.5%- 20%.
Worldwide, 50 million people live with dementia; 152 million in 2050.

- In the United States, Americans are 65 years or older, and 15% of them live with dementia. The prevalence of dementia is about 2.7% in developed countries.
- In India, 15% of people are over 60 years old. An estimated 1% of people aged 60 to 65 in urban and rural areas have dementia, according to studies.
- A study of rural Bengali elderly found that 11.3% of people over 50 years old had probable dementia, and 5.0% had definite dementia.
- Among the Xhosa-speaking community of South Africa, 11% of those older than 65 had dementia.
- According to the World Alzheimer Report, the prevalence of dementia increases with age, especially after age 65.
A study of a low-income, rural, isiXhosa-speaking community of S. Africa found that 11% of those older than 65 had dementia.
In India, 76 million people are over 60 years old. Anywhere from 1% to 3.4% of people aged 60 to 65 in urban and rural areas have dementia, according to studies.

A study of rural Bangladesh found that 11.5% of people over 60 years old had questionable dementia, and 3.6% had definite dementia.
Aboriginal Australians have one of the worst life expectancies and health outcomes. Approximately 13.4% of those older than 60 years live with dementia (3 times higher than rest of population).
41 million Latin Americans are 60 years or older, and 7.1% of them live with dementia. The prevalence of dementia in those 65 - 69 is higher than those living in developed countries.
<table>
<thead>
<tr>
<th>Year</th>
<th>Criteria</th>
<th>Sample size (n)</th>
<th>Age (years)</th>
<th>Prevalence (95% CI)</th>
<th>Causes of other dementias</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>All dementia</td>
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<tr>
<td>Asia</td>
<td></td>
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<tr>
<td>China</td>
<td>DSM-III, ICD-10</td>
<td>87761</td>
<td>&gt;65</td>
<td>3.1% (2.8-3.5)</td>
<td>2.0% (1.5-3.1), 0.9% (0.7-1.1), Mixed, PDD, DLB, FTD</td>
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<tr>
<td>2007</td>
<td>DSM-IV</td>
<td>34807</td>
<td>&gt;65</td>
<td>5.0%</td>
<td>3.5% (3.0-3.9), 1.1% (0.9-1.1), Mixed, PDD, DLB</td>
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<td>China</td>
<td>DSM-III, DSM-IV</td>
<td>7149</td>
<td>&gt;65</td>
<td>3.2% (1.5-4.9)</td>
<td>1.9% (1.2-2.5), 0.7% (0.1-1.3), Mixed</td>
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<td>(Beijing,</td>
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<td>Xian,</td>
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<td>Shanghai,</td>
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<td>Chengdu</td>
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<tr>
<td>Taiwan</td>
<td>DSM-III, DSM-IV</td>
<td>7096</td>
<td>&gt;65</td>
<td>10.1% (7.3-12.9)</td>
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<td>1994-2005</td>
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<td>&gt;60</td>
<td>3.4% (2.8-4.0)</td>
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<td>South</td>
<td>DSM-III, DSM-IV</td>
<td>14767</td>
<td>&gt;65</td>
<td>2.7% (1.4-4.0)</td>
<td>1.3% (0.8-1.8), 1.1% (0.2-1.9), Mixed, PDD, DLB, PSD</td>
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<tr>
<td>Sri Lanka</td>
<td>DSM-IV</td>
<td>703</td>
<td>&gt;65</td>
<td>3.98% (2.6-5.7)</td>
<td>2.85%</td>
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<td>2003</td>
<td>DSM-IV</td>
<td>823</td>
<td>&gt;65</td>
<td>21.1%</td>
<td>20.5%, 6.0%, Mixed</td>
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<td>Israel</td>
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<td>1366</td>
<td>&gt;65</td>
<td>5.93%</td>
<td>2.86%, 1.25%, Mixed</td>
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<tr>
<td>Wadi Ara</td>
<td>DSM-IV</td>
<td>2494</td>
<td>&gt;65</td>
<td>2.3% (1.2-3.4)</td>
<td>1.4% (0.62-2.2), 0.72%, Mixed, DLB</td>
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<td>Africa</td>
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<tr>
<td>Egypt</td>
<td>DSM-IV</td>
<td>1900</td>
<td>&gt;65</td>
<td>11.5%</td>
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<tr>
<td>1999</td>
<td>DSM-IV</td>
<td>2213</td>
<td>&gt;65</td>
<td>4.3% (3.5-5.3)</td>
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<tr>
<td>Nigeria</td>
<td>DSM-III, ICD-10</td>
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<td>Latin</td>
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<td>Cuba</td>
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<td>2002-2008</td>
<td>DSM-III, DSM-IV</td>
<td>16111</td>
<td>65 and &gt;75</td>
<td>1.8% (1.2-2.7) and 3.4% (2.3-5.6)</td>
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<td>Chile</td>
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<td>2000</td>
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<td>1532</td>
<td>&gt;65</td>
<td>6.7% (5.5-8.0)</td>
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<td>Peru</td>
<td>DSM-IV</td>
<td>2438</td>
<td>&gt;55 and &gt;65</td>
<td>8.0% (7.0-9.2) and 10.3% (8.3-13.0)</td>
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</tbody>
</table>
Black vs. White Americans

The Chicago Health and Aging Project:

- Blacks performed worse than whites on cognitive tests.
- Blacks were more likely to have prevalent Alzheimer's disease at baseline.
- Blacks had higher risk of incident Alzheimer's disease.
  - Rate of cognitive decline among blacks differed little from whites.
- Persistent differences in cognitive level between races underlie higher risk of...
- Rate of cognitive decline among blacks differed little from whites.

- Persistent differences in cognitive level between races underlie higher risk of incident Alzheimer's disease.

- These observed differences are caused by racial disparities over the lifespan:
  - Access to high quality education
  - Access to material and social resources
  - Exposure to discrimination
  - Exposure to neurotoxins
  - Access to healthcare
“I gave three years of my life to take care of my dying mother who had Alzheimer’s disease. Being there for her every need for three years might have looked co-dependent but it wasn’t because it was what I wanted to do.”

- Melody Beattie
(American author)
What is the social and economic cost of dementia around the world?

Photo: Alex Kornhuber
A proper understanding of the societal costs of dementia and how they affect families, health and social services, and governments is fundamental to raising awareness, achieving proper prioritization, and focusing efforts to improve the lives of people with dementia and their caregivers.
The global impact of dementia

Around the world, there will be 9.9 million new cases of dementia in 2015, one every 3 seconds.

46.8 million people worldwide are living with dementia in 2015. This number will almost double every 20 years.

68% 2050

Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.

The total estimated worldwide cost of dementia in 2015 is US$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to US$ 2 trillion by 2030.

If global dementia care were a country, it would be the 18th largest economy in the world exceeding the market values of companies such as Apple and Google.

This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

The World Alzheimer Report 2015 was independently researched by King's College London and supported by Bupa.
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The total estimated worldwide cost of dementia in 2015 is US$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to US$ 2 trillion by 2030.
If global dementia care were a country, it would be the 18th largest economy in the world exceeding the market values of companies such as Apple and Google.

(source: Forbes 2015 ranking).
What is the social cost of dementia?
Social Cost of Dementia

• In developing countries, the state does not provide long-term care.

• Traditional kinship structures are under threat from the demographic, social, and economic changes that accompany economic development.

• Worldwide costs of dementia used an average of 1.6 hours of informal care/day.
threat from the demographic, social, and economic changes that accompany economic development.

- Worldwide costs of dementia used an average of 1.6 hours of informal care/day.

- Living with children is the norm, and three-generation households are common.

- Around 37% of people with dementia live alone or with a spouse only.
Caregiver Burden

- Caregiver burden refers to the overall pressure of caregiving, encompassing physical, psychological, social, and financial factors.

- Studies show that caregivers tend to experience:
  - Physical and psychological stress
  - Higher risk of clinical depression
  - Higher risk of clinical anxiety
  - Higher risk of chronic medical conditions

- The lower the patient’s daily functioning, the
- Higher risk of clinical depression
- Higher risk of clinical anxiety
- Higher risk of chronic medical conditions

- The lower the patient’s daily functioning, the higher the caregiver’s burden.

- The more frequent and severe the patient’s behavioral symptoms, the higher the caregiver burden.

- The higher the sense of obligation a caregiver has, the higher the caregiver burden.
Does Caregiver Burden Vary According to the Cause of Dementia?

One study showed that, in early stages, patients with dementia caused by cerebrovascular disease (vascular dementia) imposed a greater burden on caregivers than did patients with dementia due to Alzheimer's disease (AD).

The authors highlight that this observation may be related to the fact that patients with vascular dementia tend to need care for other conditions:
- hypertension
- heart disease
- stroke
- diabetes
- heart disease
- stroke
- diabetes

In late stages of disease, relatives of AD patients experienced more caregiver burden than those of vascular dementia patients.

Anecdotally, caregiver burden varies according to dementia type during early stages of disease (frontotemporal dementia vs. AD), but caregiver burden tends to homogenize in late stages of illness.
What is the economic cost of dementia around the world?
Unpaid, "Informal" Care

• Translating the contribution of informal care into financial costs is not straightforward.

• The inputs most commonly assessed are:
  - assistance with basic activities of daily living (eating, dressing, etc.)
  - assistance with instrumental activities of daily living (finances, shopping, etc.)
  - supervision and management of behavioral symptoms
  - harm prevention

• Direct medical costs: hospital care
- Supervision and management of behavioral symptoms
- Harm prevention

• Direct medical costs: hospital care, medications, and visits to clinics.

• Direct social care costs: community services (such as home care), food supply, transportation, and residential or nursing home care.
<table>
<thead>
<tr>
<th>World Bank income region</th>
<th>Informal care (all ADLs), %</th>
<th>Direct costs, %</th>
<th>Total costs, %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Medical</td>
<td>Social</td>
</tr>
<tr>
<td>Low</td>
<td>57.6</td>
<td>28.2</td>
<td>14.3</td>
</tr>
<tr>
<td>Lower middle</td>
<td>64.7</td>
<td>23.1</td>
<td>12.2</td>
</tr>
<tr>
<td>Upper middle</td>
<td>42.2</td>
<td>32.1</td>
<td>25.7</td>
</tr>
<tr>
<td>High</td>
<td>40.3</td>
<td>14.5</td>
<td>45.2</td>
</tr>
<tr>
<td>All</td>
<td>41.7</td>
<td>16.0</td>
<td>42.3</td>
</tr>
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</table>

Aggregated costs types as percentages of total costs in the different World Bank income regions.
## Cost per person with dementia by World Bank income region

<table>
<thead>
<tr>
<th>World Bank income region</th>
<th>Informal care (all ADLs), US$</th>
<th>Direct costs, US$</th>
<th>Total costs, US$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Medical</td>
<td>Social</td>
</tr>
<tr>
<td>Low</td>
<td>500</td>
<td>244</td>
<td>124</td>
</tr>
<tr>
<td>Lower middle</td>
<td>2012</td>
<td>717</td>
<td>380</td>
</tr>
<tr>
<td>Upper middle</td>
<td>2879</td>
<td>2194</td>
<td>1755</td>
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<tr>
<td>High</td>
<td>13,244</td>
<td>4766</td>
<td>14,855</td>
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<tr>
<td>All</td>
<td>7084</td>
<td>2711</td>
<td>7191</td>
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<td>WHO region</td>
<td>Per capita costs, US$</td>
<td>People with dementia, n</td>
<td>Aggregated costs, billions of US$</td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total costs</td>
</tr>
<tr>
<td>Low income</td>
<td>5,036,979</td>
<td>4.37</td>
<td>0.24</td>
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<td>Lower middle income</td>
<td>3109</td>
<td>9,395,204</td>
<td>29.21</td>
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<td>Upper middle income</td>
<td>6827</td>
<td>4,759,025</td>
<td>32.49</td>
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<tr>
<td>High income</td>
<td>32,865</td>
<td>16,367,508</td>
<td>537.91</td>
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<tr>
<td>Total</td>
<td>16,986</td>
<td>35,558,717</td>
<td>603.99</td>
</tr>
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</table>
The contribution of each World Bank income region to the global prevalence of Dementia and to global costs

<table>
<thead>
<tr>
<th>World Bank income region</th>
<th>Proportion of overall population, %</th>
<th>Proportion of people with dementia, %</th>
<th>Informal care (all ADLs), %</th>
<th>Direct costs, %</th>
<th>Total costs, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>30.6</td>
<td>14.2</td>
<td>1.0</td>
<td>1.3</td>
<td>0.2</td>
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<td>Lower middle income</td>
<td>38.5</td>
<td>26.4</td>
<td>7.5</td>
<td>7.0</td>
<td>1.4</td>
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<tr>
<td>Upper middle income</td>
<td>13.0</td>
<td>13.4</td>
<td>5.4</td>
<td>10.8</td>
<td>3.3</td>
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<tr>
<td>High</td>
<td>17.8</td>
<td>46.0</td>
<td>86.1</td>
<td>80.9</td>
<td>95.1</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Number of people living with dementia in millions (black box) per geographic area in 2015 (light grey), with projections for 2030 (dark blue) and 2050 (dark grey). Corresponding percentage increase compared to 2015 is depicted in red labels.
How does dementia measure up?

Dementia (23) 27647 4882
Cancer (12) 5999 129,269
Heart disease (8) 3455 73,153
Stroke (5) 4770

48 Billion
Dementia Research and Equity

Photo: Alex Kornhuber
Inequitable Research on Dementia

• Only 10% of studies on dementia are conducted in developing countries.

• The World Health Organization initiated a dementia research prioritization exercise.
  - The theme, "Dementia Risk Reduction" was the most prevalent among the thematic research avenues.
Mean of the top 20 Thematic Research Avenues’ priority scores for each of the seven overarching research goals across the five scoring criteria.
“Not everything that is faced can be changed, but nothing can be changed until it is faced.”

- James Baldwin (American writer and activist)
References:

Thank you

Dr. Shamiel A. McFarlane
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UCSF

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