Demographics of Dementia and Dementia Caregiving in the United States

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Key Points

Dementia has a large and growing health, social, and economic impact in the US and around the world

**Dementia is the most costly chronic disease in the US**

Aging is unequal in the US, and getting more so

**Dementia has a disproportionate impact on women, racial / ethnic minorities, and those with less education and wealth**

Despite recent encouraging news regarding declining dementia incidence and prevalence, the large growth in the elderly population will lead to many more people with dementia in the decades ahead

**This increase in cases will place added burdens on the declining pool of family caregivers and on public programs**

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An Aging World Will Have Many More People with Dementia
The Demographic Imperative
World Population, Age 65+ and Age <5

Source: Population Reference Bureau

Declining Availability of Caregivers:
US Old-Age Dependency Ratio

Growing Life Expectancy Differences in the United States


Older Adults with Dementia in the US
HRS-ADAMS Estimates of 2012 US Population Prevalence, Age 65+

- Normal: 72%
- MCI: 19%
- Dementia: 9%

**US Population, Age 65+:**
- Dementia: 4.0 – 4.5 million
- MCI: 8.0 – 8.7 million


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Expected Future Years of Dementia at Age 50:
Women in the United States

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Years of Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>FB Hispanic</td>
<td>5</td>
</tr>
<tr>
<td>US Hispanic</td>
<td>4</td>
</tr>
<tr>
<td>African-Am</td>
<td>3</td>
</tr>
<tr>
<td>White</td>
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</tr>
</tbody>
</table>

Causes for Racial / Ethnic and SES Disparities in Dementia Risk?

- Differences in life-course SES conditions?:
  - Parental education, childhood health, educational attainment and quality, occupation, income / wealth, social networks, stress, nutrition, neighborhoods
- Disparities in CV risk factors and health behaviors?
- Pollution / environmental exposures?
- Genetics: ApoE e4?


Differences in Social Support for Older Adults with Dementia in the US
Living Arrangements of US Adults 65+ with Dementia


Living Arrangements of US Women 65+ with Dementia, by Race / Ethnicity

Caregivers for Older Adults with Dementia in the US

The Intensity of Informal Caregiving for Older Adults with Dementia

• NHATS / NSOC Data, Age 65+ with Dementia, in Community or Residential Care, 2011
  – **5.8 million** caregivers
  – Providing an average of **92 hours per month** of care
  – From 57% (community) to 75% (residential care) of caregivers had provided care for **4 or more years**
  – Total hours of informal care for dementia: **6 billion / yr**

Source: Kasper et al, Health Affairs, 2015.
Informal Caregivers in the United States, HRS, 2010

Probability of Receiving Intensive (> 200 Hours) Informal Care in the Past Month for Those With Dementia, HRS, 2010

Friedman et al, Health Affairs, 2015.
Dementia Annual Cost Per Case
United States, 2010, HRS Data

- Informal Care: 49%
- Nursing Homes: 25%
- Out of Pocket: 11%
- Home Care: 10%
- Medicare: 5%

Total: $50,000 per case;
$200 billion nationwide

Source: Hurd et al., NEJM, 2013.

Lifetime Cost of Dementia

Source: Jutkowitz et al., JAGS, 2017.
Conclusions

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Research Recommendations

**What are the causes and implications of the growing disparities in life expectancy and dementia risk among older US adults?**

What interventions across the life-course will reverse the growing disparities in length and quality of life in the US?

**How are caregiving responsibilities divided among families from different racial/ethnic and SES groups?**

What are the implications for caregivers’ health and wealth?

How can we support caregivers to minimize the BURDENS and maximize the BENEFITS of caregiving?

How will caregiving be divided in the future as the number of available family caregivers declines?
Research Recommendations

How are older adults with dementia and their families utilizing new residential care options?
What information will help families make good choices about community vs. assisted living vs. nursing home care?

Since dementia has a disproportionate impact on racial and ethnic minorities and those with low SES:
Representative population-based studies that include (or oversample) these individuals are especially important to gauge the full impact of dementia in the US population.

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- Alzheimer’s Association
THANK YOU