


# Demographics and Care Post-Diagnosis



*Advisory Council on Alzheimer's Research, Care,  
and Services Meeting*

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No disclosures to report

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## My Path to Geriatrics & Aging Research









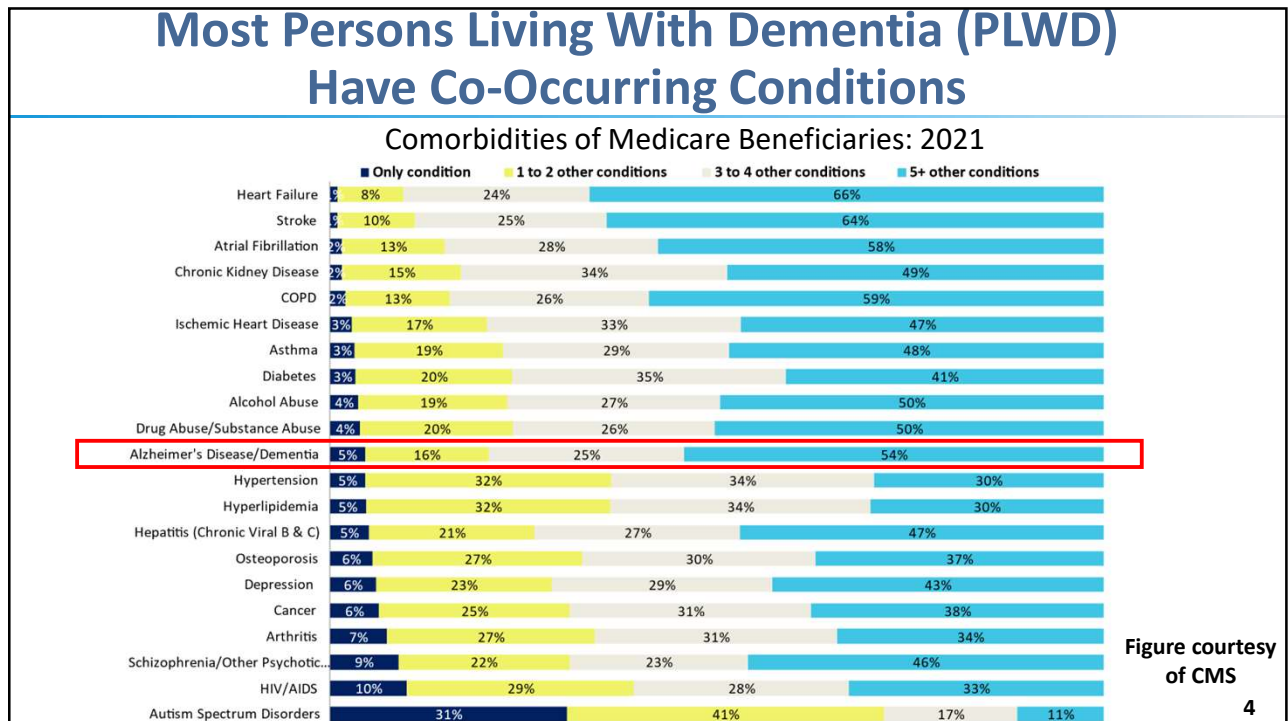


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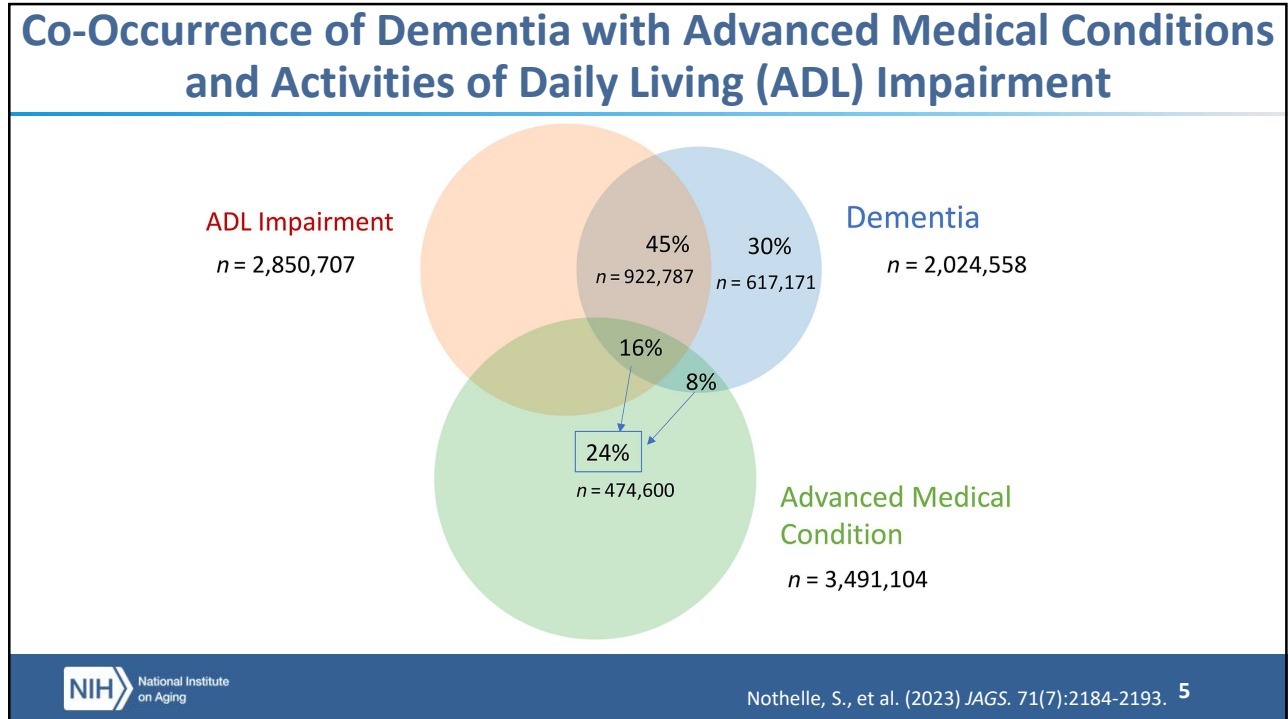
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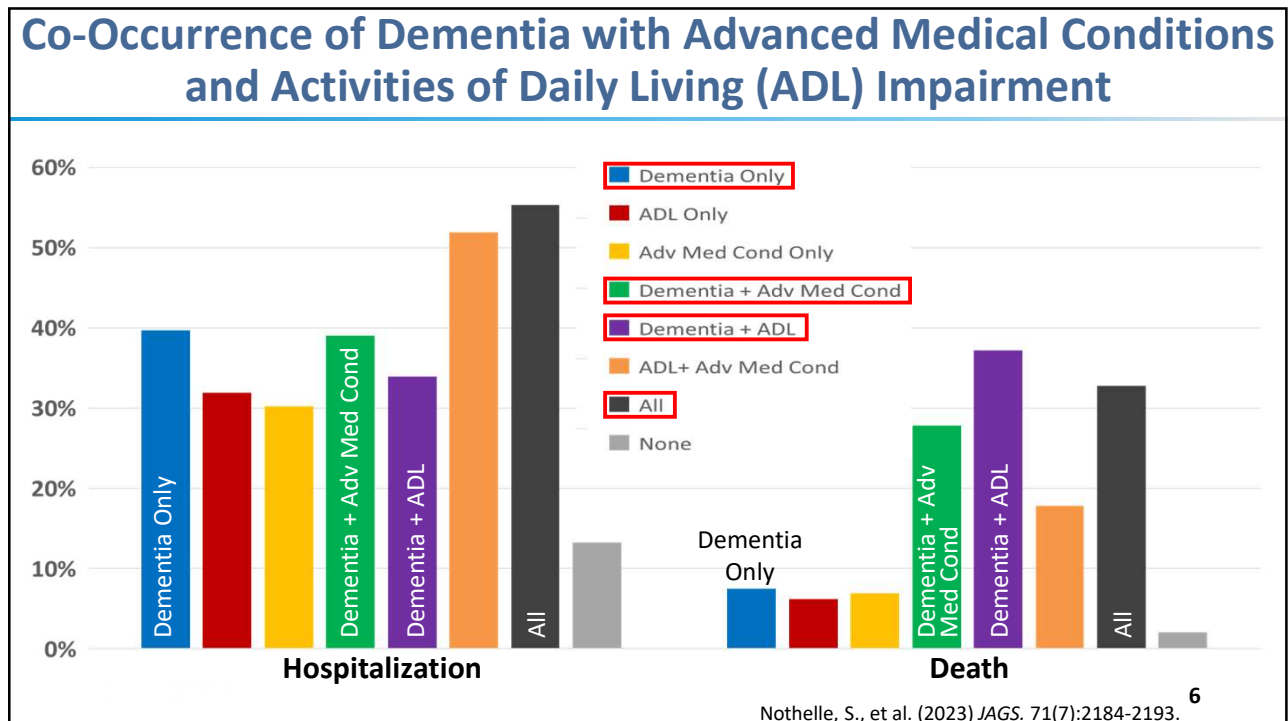
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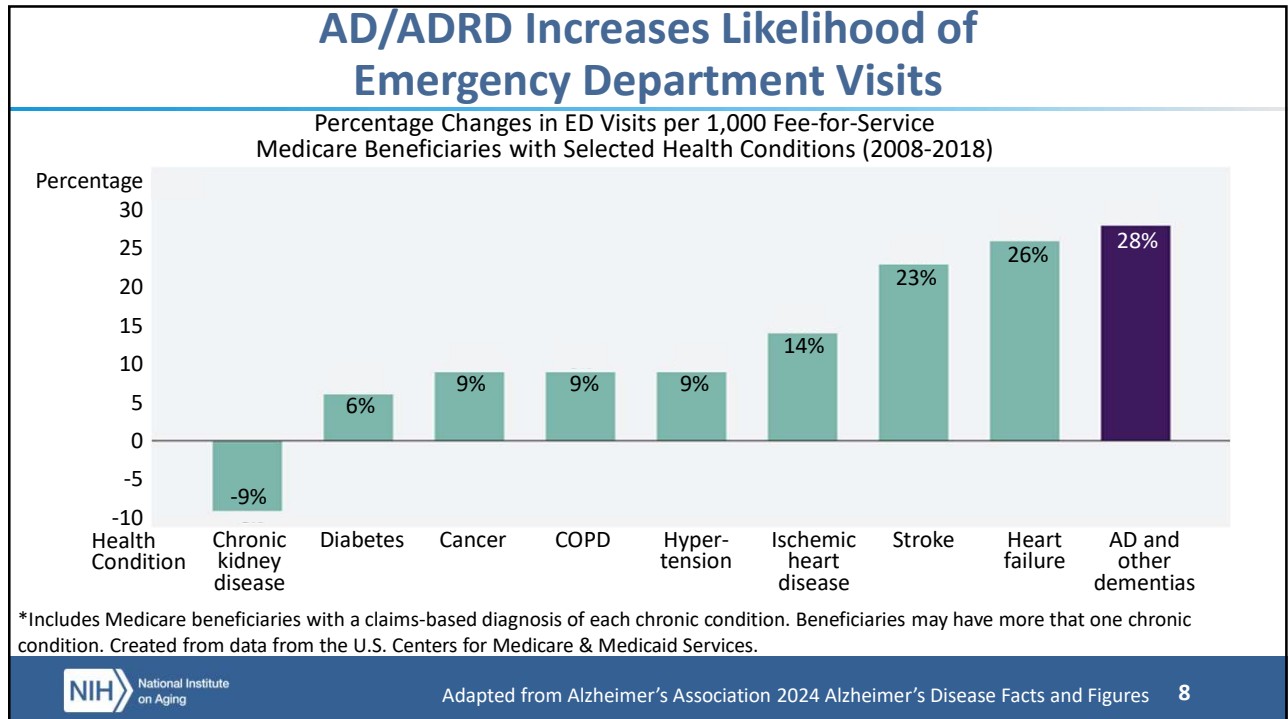


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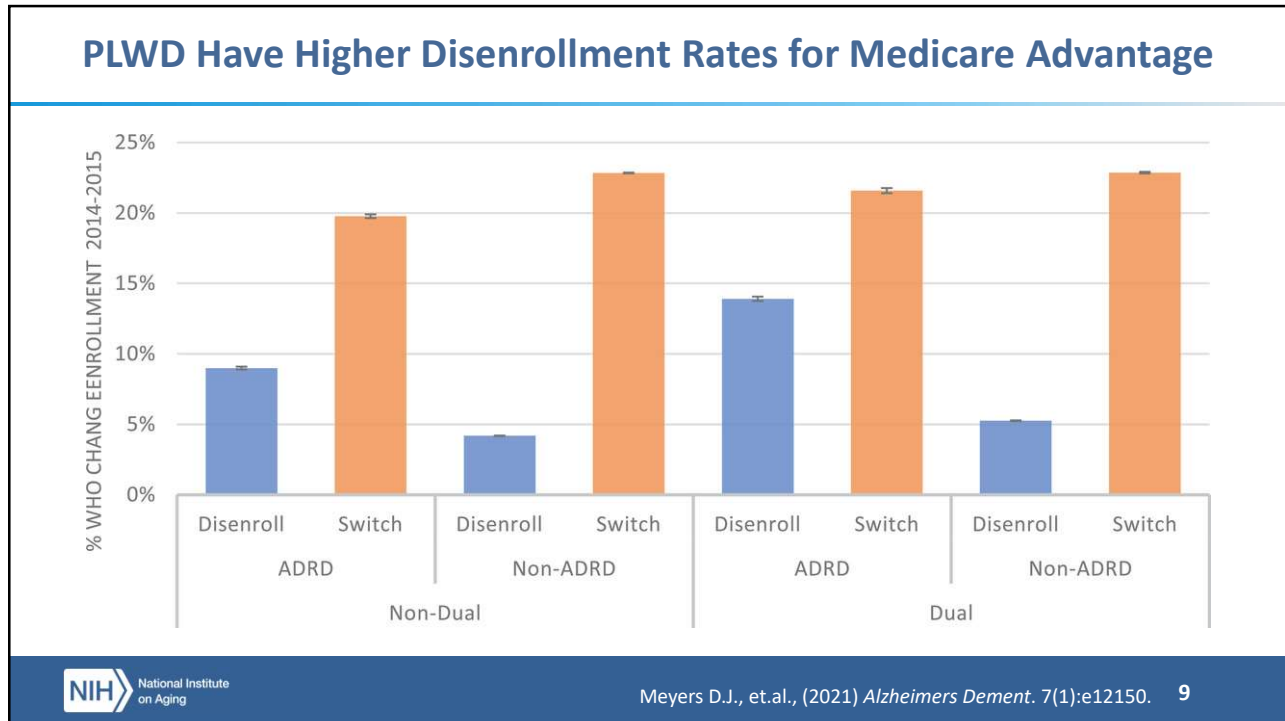
## Challenges for Dementia Care

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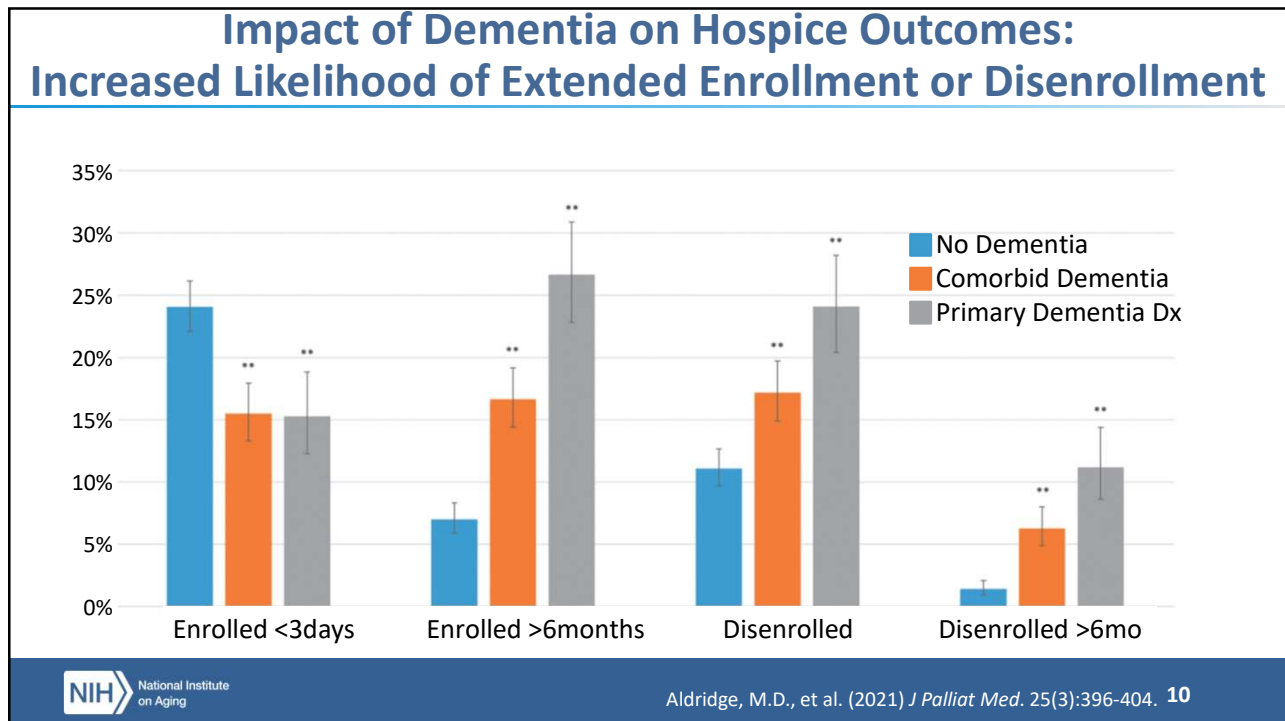
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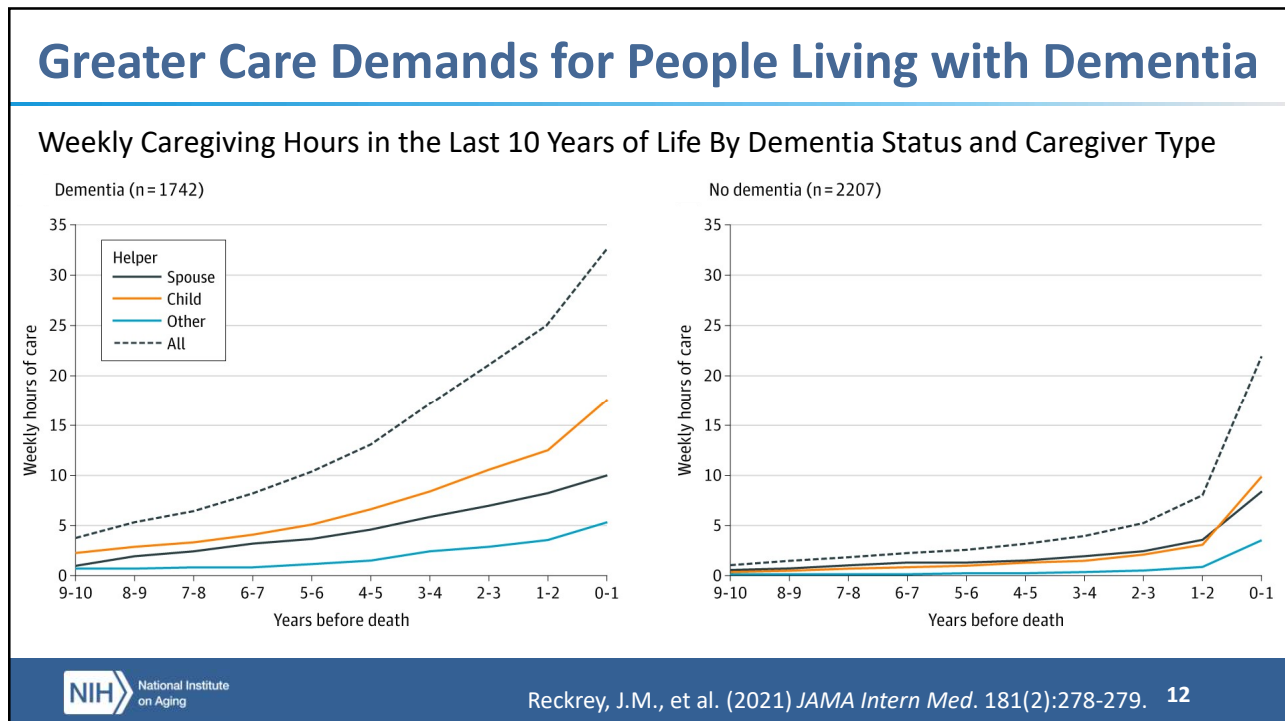


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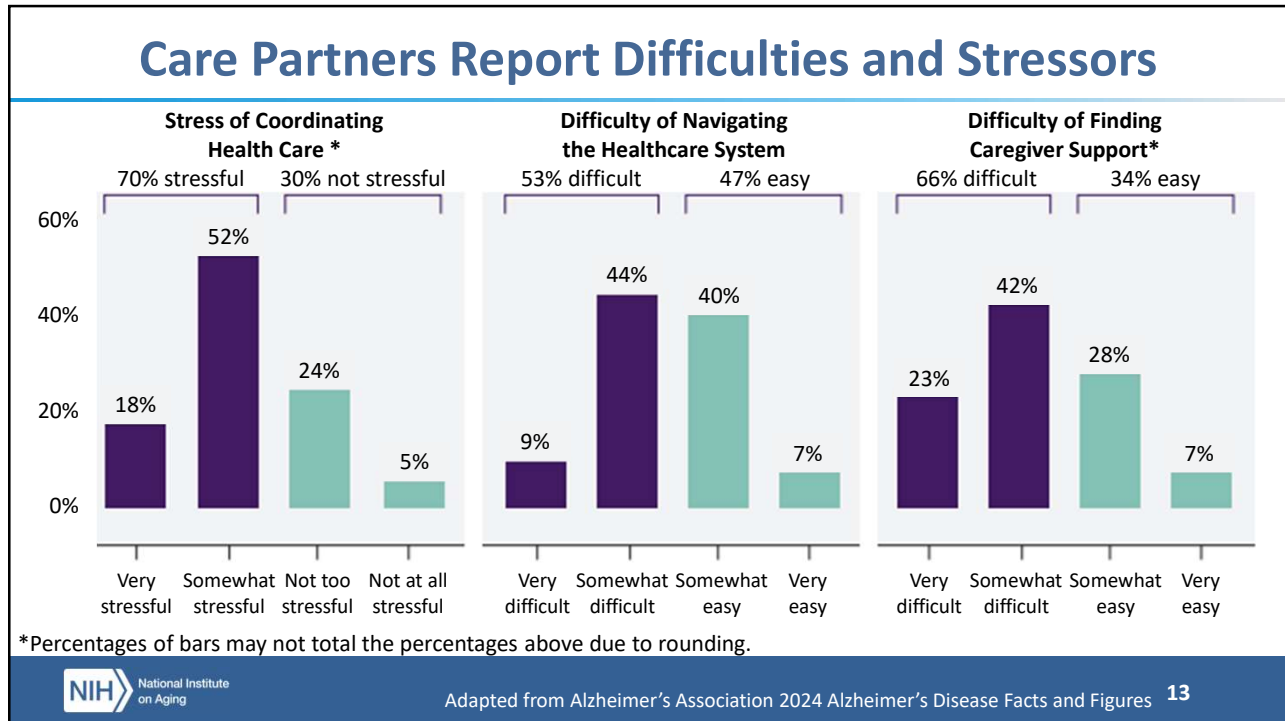
**Impact on Care Partners and Families**

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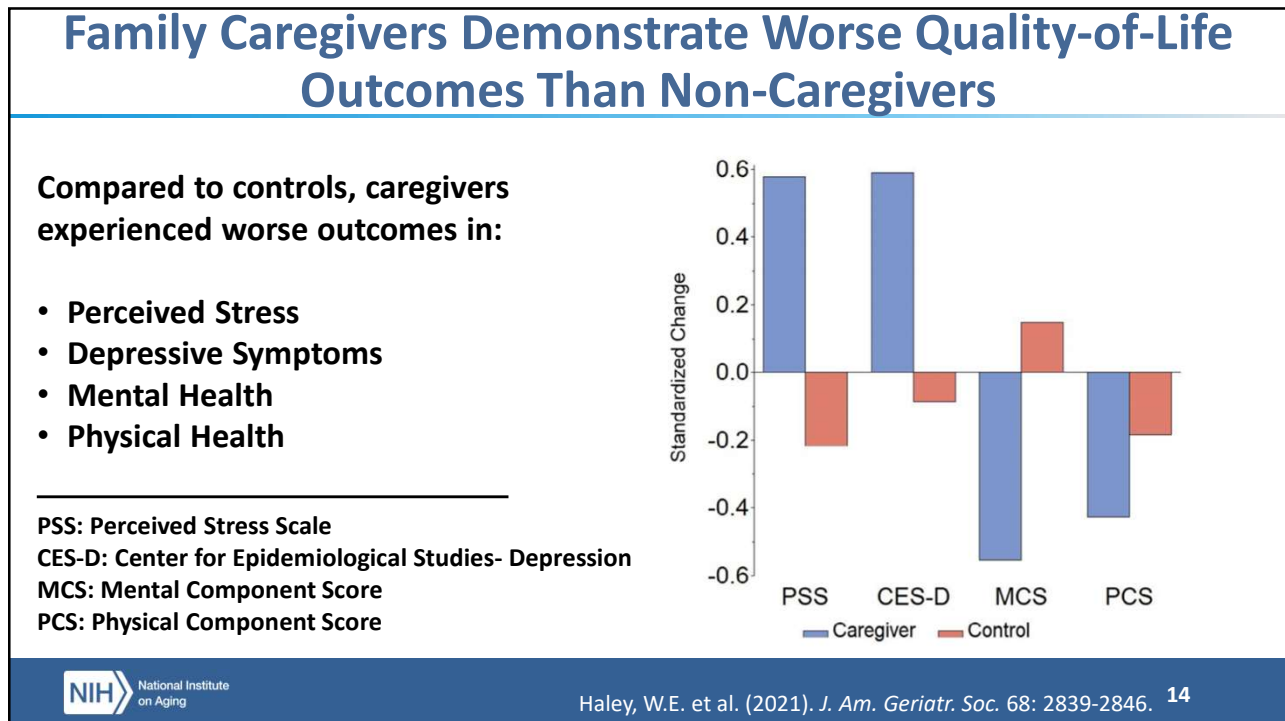
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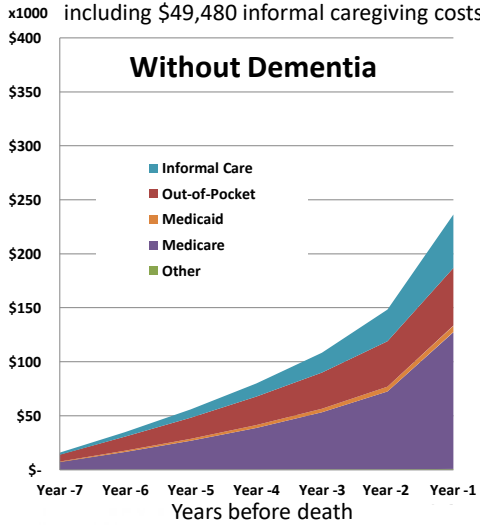
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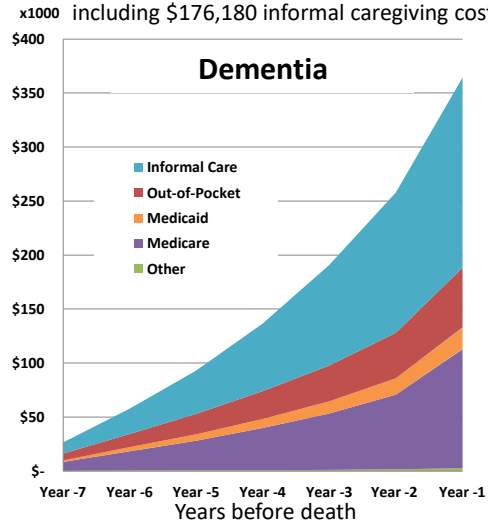
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## Cumulative Costs are Greater for Community Residents Living with Dementia

Families of Community-Dwelling Individuals Without Dementia shoulder a lower proportion of costs, including \$49,480 informal caregiving costs.



Families of Community-Dwelling Individuals with Dementia shoulder a **greater proportion of costs**, including \$176,180 informal caregiving costs.



Kelley, A.S., et al. (2020). *JAGS*: 68(6):1319-1324. 15

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### Examples of Relevant NIA Efforts

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## NIA-Supported Care/Caregiver Research

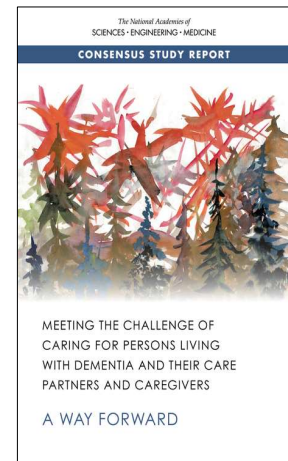
- NIA's broad research portfolio includes, but is not limited to:
  - work investigating the quality, effectiveness, and access of different models of dementia care and care coordination
  - studies of the economic impact of dementia care on individuals, families, and society
  - efforts aimed at helping develop and evaluate effective training and other supportive resources for individuals caring for people with dementia



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## Exploring Interventions for Dementia Care & Caregiving

- **NIH commissioned a two-part study in 2018 –**
  - AHRQ conducted a systematic evidence review of the existing literature
  - NASEM developed a comprehensive report on the evidence base for dementia care and caregiving interventions
- **Key Messages:**
  - Most caregiving interventions were not assessed because they had small sample sizes, were pilots, or had high risk of bias
  - **Recommendations included implementing and evaluating outcomes for two types of interventions:**
    - **Collaborative Care Models**
    - **Resources for Enhancing Alzheimer's Caregiver Health (REACH) II**
  - The report recommends broader implementation of these programs in real-world settings that allow for continual monitoring, evaluation, and quality improvement



*released in February 2021*

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## CMS Guiding an Improved Dementia Experience (GUIDE) Model

- In July 2023, CMS announced a **new voluntary care model, the GUIDE Model**, which holds promise for improved dementia care and dementia caregiving. This is an example of a Collaborative Care Model indicated by the NASEM report.
- This team-based collaborative care approach aims to support people living with dementia and their unpaid caregivers by addressing the key drivers of poor-quality dementia care.
- The GUIDE Model will focus on dementia care management and aims to **improve quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities**. It will achieve these goals through a comprehensive package of care coordination and care management, caregiver education and support, and respite services.

## Emergency Departments Leading the Transformation of Alzheimer's and Dementia Care (ED-LEAD) Study

- Awarded in 2023, ED-LEAD is a 5-year NIA cooperative agreement to lead a large nationwide multi-site embedded pragmatic clinical trial **to advance care delivery for people living with dementia and their care partners who visit the emergency department**.
- The study will test three interventions—redesigning the emergency department experience, nurse-led telephone-based care, and transitional care delivered by paramedics—**to reduce future emergency department visits and hospital admissions and improve quality of care and care coordination**.

## IMPACT Collaboratory: A National Resource

- The Collaboratory is a national resource for embedded pragmatic clinical trials to **improve the care and health outcomes of persons living with dementia** and their care partners.
- The Long-Term Care Data Cooperative** is the largest integrated database of electronic health record data from nursing homes in the U.S. More than 2,000 facilities are enrolled, representing 500,000+ residents.
- Linkages with Medicare claims establish a data infrastructure to monitor future public health emergencies and the impact of treatment and policy changes.



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Thank you

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