

Dementia Caregiving in the U.S.

A secondary data analysis of the Caregiving in the U.S. 2015 Report

Research Recommendations

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July 28, 2017
NAPA Advisory Council

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About the National Alliance for Caregiving

- Nonprofit coalition of over 50 national organizations focused on family caregiving issues
- Established in 1996 to support family caregivers and the professionals who work with them
- NAC Activities:
 - Conduct research and policy analysis;
 - Develop national programs;
 - Strengthen state and local coalitions;
 - Increase public awareness;
 - International work and awareness.

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About *Dementia Caregiving in the U.S.* (February 2017)

- Conducted in partnership with the Alzheimer's Association and supported by Home Instead Senior Care & Eli Lilly
- Secondary analyses of the nationally representative study, *Caregiving in the U.S. 2015*, comparing 372 dementia caregivers to 963 non-dementia caregivers
- Respondents include anyone who indicated the presence of Alzheimer's disease, dementia, or other mental condition as a primary or additional condition requiring care

Report available at <http://bit.ly/DementiaCare17>

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Report Topics

- Detailed findings on dementia caregivers, including:
 - Demography and caregiving tasks
 - Spotlights on Millennials, Grandchildren Caring for Grandparents, Long-Distance, Male, and Spousal Caregivers
- Information on navigating the health care system and presence of other help, such as home care providers
- Financial and Workplace Impacts of dementia caregiving
- Promising interventions for dementia caregivers

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The Big Picture

- 22% of America's 44 million family caregivers care for someone with dementia (roughly 9.6 million people)
- The "typical" dementia caregiver is a woman, approximately 54 years old – about six years older than the typical non-dementia caregiver
- Dementia caregivers shoulder a higher burden than others, providing roughly 28 hours of care per week
- 2 out of 3 perform medical/nursing tasks, half of whom have no prior training

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Promising Models of Care

- **Partners in Dementia Care:** a telephone-based care coordination and support service intervention program, implemented by the Veterans Health Administration (VHA) and regional Alzheimer's Association chapters
- **REACH VA:** Studied in an NIA randomized controlled trial, Resources for Enhancing Alzheimer's Caregiver Health (REACH II), provided family caregivers assistance through education, support, and skills-building both in-home and via telephone

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Research Findings & Proposed Future Directions

Key Finding

The average person receiving care (the person with Alzheimer's disease or another form of dementia) is 77.2 years old, significantly older than other care recipients who are supported by a family caregiver, and more than a third of care recipients are 85 or older (27%). A quarter of dementia caregivers over age 75 report worse health due to caregiving.

Future Research Areas

Examine ways to increase geriatric and dementia-specific training for dementia caregivers.

Analyze the needs of "the oldest old" including support for dementia caregivers and the unique care needs of those with dementia over age 75.

Research Findings & Proposed Future Directions

Key Finding

State Medicaid programs have shifted long-term care services from institutional care to home and community based services as a way to reduce unnecessary costs and to meet the growing demand for these services. With regard to dementia care, almost half of dementia care recipients live in their own home (40%), and of those recipients, many live alone (47%). A third of dementia caregivers are co-residents with the person with dementia (33%). Co-resident caregivers often experience higher strain and caregiving burden.

Future Research Areas

Understand the dynamic between the caregiver and home care providers in supporting a safe home environment for the person with dementia.

Examine whether home-care providers can provide training and respite to the dementia caregiver that delays the institutionalization of the person with dementia.

Research Findings & Proposed Future Directions

Key Finding

Dementia caregivers are nearly twice as likely to say that their health has gotten worse as a result of their caregiving responsibilities. More than one in three dementia caregivers say their health has declined (35%), versus just one in five non-dementia caregivers.

Future Research Areas

Develop a comprehensive dementia caregiver assessment to determine the health, willingness, and ability of the dementia caregiver to provide care.

Identify resources that can help dementia caregivers engage in self-care.

Research Findings & Proposed Future Directions

Key Finding

Employed dementia caregivers work an average of 34.9 hours per week while caregiving, and more than half (57%) work full time. Two in three employed caregivers report that they had to make workplace accommodation in some way (statistically significantly higher than the 59% of non-dementia caregivers). Fifteen percent either gave up work entirely or retired early to provide care.

Future Research Areas

Identify and evaluate “low-cost, no cost” workplace accommodations (such as flexible workplace environments and paid leave) that can be adapted to meet the needs of working dementia caregivers in order to protect their financial security.

Research Findings & Proposed Future Directions

Key Finding

Dementia caregivers want greater support from healthcare professionals. Less than half of dementia caregivers (44%) report having a doctor, nurse, or social worker *ever* ask them what they need to care for their loved one. Moreover, only a quarter (24%) have *ever* been asked about their own self-care needs.

Future Research Areas

Identify and evaluate technologies that can simplify care planning for the family caregiver and the person with dementia.

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Research Findings & Proposed Future Directions

Key Finding

Many dementia caregivers want to be kept more involved in their loved one's medical care. More than half would find it helpful to require health providers to include their name on their care recipient's chart (56%).

Future Research Areas

Conduct research in the area of shared decision making to assess whether shared-decision making (SDM) plays a role in care planning between caregivers and providers as well as potential ways to increased SDM between these groups.

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Research Findings & Proposed Future Directions

Key Finding

One out of four (27%) dementia caregivers has never made use of respite care but wants to do so. This indicates that there is a need among some dementia caregivers for easily accessible respite services.

Future Research Areas

Examine ways to promote greater access and awareness of respite care, as well as identify effective characteristics of respite care.

Research Findings & Proposed Future Directions

Key Finding

When many dementia caregivers need resources to assist them with caregiving, they cannot access these needed resources. In fact, 28% of dementia caregivers encounter difficulties in finding affordable services in their communities.

Future Research Areas

Examine ways to expand caregiver access to long-term services and supports. Explore potential support models for caregivers including options for individual and family counseling, caregiver support groups, and a call-in phone line offering immediate assistance to dementia caregivers.

To Learn More

- Save the Date: August 2nd at 3 PM ET
National Webinar on Dementia Care
webcaster4.com/Webcast/Page/9/21724
- Download the Report:
<http://bit.ly/DementiaCare17>
- Final Research Recommendations forthcoming, as a pre-summit activity in advance of the October 2017 NIH Research Summit on Dementia Care
- Alliance CEO Gail Gibson Hunt will share key findings from the *Dementia Caregiving* report at the Summit

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Thank You!

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July 28, 2017 -- Advisory Council Meeting #25

The meeting was held on Friday, July 28, 2017, in Washington, DC. The Advisory Council spent the morning discussing information gaps across the three areas of research, clinical care, and long-term services and supports. There was also a presentation on the recently released National Academy of Sciences, Engineering, and Medicine (NASEM) report on preventing cognitive decline. Additional presentations included a presentation on planning and progress towards the October Care and Services Summit and federal workgroup updates. Material available from this meeting is listed below and is also available at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Jul2017>.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Presentation Slides

2017 National Plan Update and Non-Federal Recommendations	[HTML Version] [PDF Version]
Clinical Services Subcommittee Federal Update	[HTML Version] [PDF Version]
CommunityRx for Community-Residing People with Dementia and Their Caregivers	[HTML Version] [PDF Version]
Dementia Caregiving in the U.S.	[HTML Version] [PDF Version]
Development of the FY 19 NIH Bypass Budget for Alzheimer's Disease and Related Dementias	[HTML Version] [PDF Version]
Implications of a Biologically Based Definition of Alzheimer's Disease	[HTML Version] [PDF Version]
Increasing Opportunities for Choice and Control for Persons with Dementia	[HTML Version] [PDF Version]
Interventions to Prevent or Slow Cognitive Decline, MCI and Dementia in Individuals without Dementia	[HTML Version] [PDF Version]
Living Alone With Dementia	[HTML Version] [PDF Version]

Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Managing Chronic Conditions in People Living with Dementia	[HTML Version] [PDF Version]
Preventing Cognitive Decline and Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care	[HTML Version] [PDF Version]
The Many Challenges of Alzheimer's Disease	[HTML Version] [PDF Version]

Videos

Welcome thru Clinical Care	[Video]
LTSS Research	[Video]
Public Comments thru Federal Workgroup Updates	[Video]
Recommendations thru Adjourn	[Video]

Last Updated: 06/27/2018