

# Dementia Caregiving in the United States Research Recommendations

National Alliance for Caregiving

[www.caregiving.org](http://www.caregiving.org)



#DementiaCareSummit

## About the Reports

- 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 indicated that that Alzheimer's disease, dementia, or other "mental confusion" was the problem or illness requiring care
- Research recommendations draw from research findings and existing gaps



National Alliance for Caregiving in partnership with the Alzheimer's Association, *Dementia Caregiving in the U.S. (February 2017)* available at [www.caregiving.org/research/condition-specific](http://www.caregiving.org/research/condition-specific). See also, *Dementia Caregiving in the U.S.: Research Recommendations (October 2017)*, at [www.caregiving.org/research/condition-specific](http://www.caregiving.org/research/condition-specific).

**Figure 30: Demographic Summary by Caregiver Type**

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
<b>Caregiver Gender</b>		
Male	42%	40%
Female	58%	60%
<b>Age of Caregiver</b>		
18 to 34	16%	26%*
35 to 49	17%	25%*
50 to 64	41%*	31%
65 to 74	16%*	11%
75 or older	10%	7%
Mean age	53.9*	48.1
<b>Race/Ethnicity of Caregiver</b>		
White non-Hispanic	66%	60%
Hispanic	13%	18%*
African American non-Hispanic	13%	13%
Asian American <sup>a</sup>	6%	6%
Other	2%	3%

<sup>a</sup> Asian American is inclusive of those caregivers who are of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, and Pacific Islands.

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**Figure 6: Hours of Care per Week**

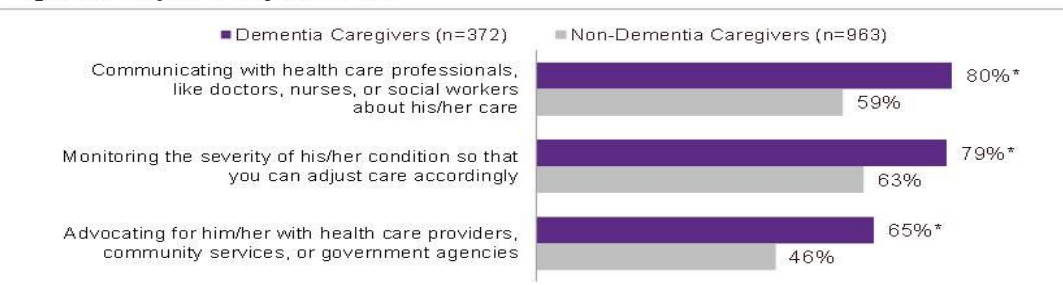
Q25: About how many hours do/did you spend in an average week helping him/her?

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Fewer than 9 hours	39%	48%*
9 to 20 hours	24%	21%
21 to 40 hours	9%	10%
41 or more hours	26%	22%
Average hours of care provided per week	27.8*	23.7

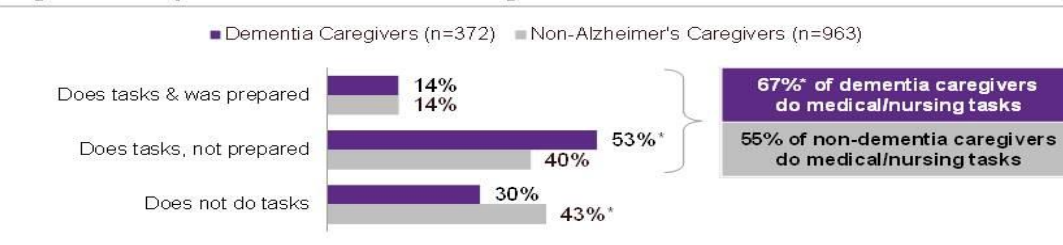
<sup>a</sup> Any caregiver who indicated providing care in excess of 98 hours per week is capped at this level, which is equivalent to 14 hours per day. Caregivers who selected constant care were capped at 77 hours per week, the mean hours of care derived from an imputation model predicting hours of care provided. For more details on mean imputation, see Caregiving in the U.S. 2015 Appendix B, Detailed Methodology.

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**Figure 9: Help with Key Activities**



**Figure 10: Preparation with Medical/Nursing Tasks**



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## Research Recommendations

- 1. Develop Geriatric-Specific Training for Older Caregivers**  
 Examine ways to increase access to geriatric and dementia-specific training for dementia caregivers. Analyze the needs of “the oldest old,” including support for dementia caregivers & the unique care needs of those with dementia over age 75.
- 2. Examine Dynamics Between Home Care and the Dementia Caregiver**  
 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.
- 3. Develop a Comprehensive Caregiver Assessment**  
 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.
- 4. Identify Scalable Workplace Accommodations**  
 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 to protect their financial security.

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# Research Recommendations

5. **Evaluate Care Planning Technologies for Dementia Caregivers**  
Identify and evaluate technologies that can simplify care planning for the family caregiver, the person with dementia, and the healthcare provider.
6. **Examine Shared Decision-Making Among Patient, Provider, Caregiver**  
Conduct research on shared decision-making (SDM) to assess whether it plays a role in care planning between caregivers and providers as well as potential ways to increase SDM between these groups.
7. **Understand Access Barriers to Respite Care**  
Develop a comprehensive dementia caregiver assessment to determine. Examine ways to promote greater access and awareness of respite care, as well as identify effective characteristics of respite care.
8. **Identify Pathways for LTSS for Dementia Caregivers**  
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.

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