

The Disproportionate Impact of Dementia on Family and Unpaid Caregiving to Older Adults

Take Away Points

- Dementia is prevalent among the aged population, and family members contribute immensely to the care of these adults. One in ten older adults not living in nursing homes have dementia, and one in three family and unpaid caregivers for older persons are engaged in caring for a person classified as having dementia. In 2011, 5.7 million caregivers contributed 532 million hours of assistance per month to the care of an older adult with dementia.
- Understanding the characteristics of caregivers and the patterns of caregiving will help in the development of support services for caregivers.

The Issue

With a significant increase in the proportion of adults living into their eighties and nineties, the growing costs and challenges of caring for older adults with Alzheimer's and other types of dementia are affecting the economy and policy. Older adults classified as having dementia are mostly cared for by their family members who they depend on for help and assistance with everyday activities including personal care and household activities. Although extant studies document the numbers of caregivers who assist older adults with disabilities and the types of assistance that these caregivers provide, little is known about the proportion and components of caregiving specific to dementia. To address gaps in knowledge about trends in caregiving for adults with dementia, this study examined 1) how caring for people with dementia fits within the broader context of all caregiving to older adults, and 2) caregiving to older adults in residential care settings and 3) the role of such settings in providing supportive services for persons with dementia.

Source

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Study Methods and Design

The study employed survey methodology where data from respondents were weighted and extrapolated to provide nationally representative estimates, taking into account differential probabilities of selection and nonresponse. Data for the study come from two linked data sets 1) the 2011 National Health and Aging Trends Study—a longitudinal study of trends and trajectories of late-life disability that is representative of Medicare beneficiaries ages 65 and older, and 2) the 2011 National Study of Caregiving—a survey of family and unpaid caregivers (up to 5 caregivers per recipient) to participants in the National Health and Aging Trends Study who received self-care, mobility, or household activity assistance. Total sample for the study included 2,423 adults (age 65 and older) and their 1,924 family and unpaid caregivers.

Core variables of interest included: probable dementia (measured by clinical diagnosis of dementia or Alzheimer's disease and/or scores on the AD8 informant interview in dementia, or impairment based on cognitive tests that evaluate memory, orientation, and executive function); self-care activities (e.g., bathing, eating, using the toilet, getting out of bed, etc.); household activities (e.g., doing laundry,

preparing hot meals, paying bills or doing banking, etc.); and assistance, i.e., any help with self-care or household activities for health or functioning reasons.

Key Findings and Limitations: Results were presented as weighted estimates and interpreted as percentages of the total older adults living in the US.

Description of older adults:

- 9.7% of the 37 million older adults living in the US in 2011 had dementia and were in residential settings other than nursing homes. About 26% of older adults received assistance with self-care and/or household activities.
- 3.6 million adults were classified as having dementia. Compared to older adults without dementia, those having dementia were more likely to receive assistance for health and functioning reasons (77.2% vs. 20.3%); less likely to live alone and more likely to live with a son/daughter or other relatives; and more likely to have three or more caregivers (29.5 % vs. 23.0 %) and receive paid help (30.1% vs. 20.5 %).

“Caregivers provided 1.3 billion hours of help per month, of which 41% (i.e., 532 million) was directed to older adults with dementia. Regardless of the recipient’s dementia status, about three-fifths of the hours were provided by spouses and daughters, and two-thirds were provided by caregivers who lived with the care recipient. More than 90% of all hours were provided to older adults living in the community.”

Description of caregivers and patterns of caregiving

- About 17.1 million caregivers cared for older adults with 1 in 3 (34%) caring for someone with dementia. Of those who cared for someone with dementia, 83% provided care in traditional community settings and 17% provided care in residential care settings.
- In community settings, caregivers for adults with dementia were more likely to be daughters and less likely to be spouses, when compared to caregivers for those without dementia. Regardless of the dementia status of the care recipient, about 50% of caregivers provided help for four or more years, with caregivers to those with dementia providing care for longer periods.
- Among caregivers in residential settings, relationships between recipient and caregivers did not differ by dementia status. However, care duration differed—47% of caregivers for those with dementia had provided assistance for six years or more (vs. 29% for those without dementia).
- The intensity of help was significantly greater for daughters (102 vs. 65 hours) and caregivers (143 vs. 97 hours) who cared for someone with dementia, compared to daughters and caregivers for those without dementia.
- Regardless of dementia status, however, care intensity was higher in traditional community than residential care settings.

Limitations: Measures of caregiver assistance and time commitment are subject to recall bias; and classification of probable dementia relied more on self-report than clinical assessment hence possibility of measurement errors.

Final Thoughts

Dementia plays a significant role in late-life family care giving. One-third of unpaid caregivers to older adults cared for someone with dementia. The findings of this study hold many implications for research and policy related to aging and caregiving. Despite the staggering number of hours by family members contributing to care for those with dementia, little research evaluates the effects and implications of caregiving on caregivers and their personal lives, including the impact on the overall economy.