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## US Prevalence And Predictors Of Informal Caregiving For Dementia

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### Abstract

In 2010, 5.5 million US adults ages seventy and older received informal care, including 3.6 million with cognitive impairment or probable dementia. Adults with probable dementia received 171 hours of monthly informal care, versus 89 and 66 hours for cognitively impaired without dementia and cognitively normal adults, respectively.

Dementia, defined as a cognitive decline severe enough to require help with daily activities, costs an estimated \$159–\$215 billion per year in the United States.[1] As much as 84 percent of this amount is attributable to long-term services and supports, many of which are provided by relatives and friends of the person with dementia. However, the reliance on informal care from family members may be unsustainable as the population ages; family sizes shrink; and women, who traditionally bear most of the burden of informal caregiving, increasingly participate in the workforce. To assess whether demographic changes will affect informal caregiving for dementia, policy makers need reliable estimates of the number of informal caregivers and care recipients and of the intensity of care provided. Yet to our knowledge, only three studies have examined these numbers.[2–4]

Most recently, Brenda Spillman and coauthors, using 2011 data from the National Survey of Caregiving, found that 18 million caregivers provided care to 9 million adults.[4] Of those caregivers, 8.5 million provided care to recipients with possible or probable dementia who did not live in nursing homes.

Using data from the 2010 Health and Retirement Study (Exhibit 1), we estimated a smaller amount of informal care: Approximately 5.5 million US adults ages seventy and older received informal care, of whom 3.6 million had cognitive impairment or probable dementia. [5]

The current study also extends previous work by examining whether the relationship of the caregiver to the recipient differs according to dementia status and by identifying independent predictors of the receipt of intensive caregiving.

## Study Data And Methods

### Data

As noted above, we used data from the 2010 Health and Retirement Study, which is a nationally representative survey of adults ages fifty-one and older and their spouses. Probable dementia and cognitive impairment but no dementia were coded using the probabilities developed by Michael Hurd and coauthors.[1]

Briefly, those authors estimated a model of probable dementia status based on the Aging, Demographics, and Memory Study, which included a detailed clinical assessment for dementia for a subsample of Health and Retirement Study respondents. Hurd and coauthors then used this model to predict the probability of dementia for the full survey sample of the Health and Retirement Study ages seventy and over, with a similar model estimated for proxy respondents (that is, people who responded to the survey questions on behalf of a sample member who was unable to participate). Using these predicted probabilities, the authors categorized respondents into one of three groups: people with probable dementia, those with cognitive impairment but no dementia, and those with normal cognitive function. We used the same three groups in our analyses.

### Analyses

We calculated total hours of care in the past month using information on in-home caregiving for assistance with activities of daily living (such as eating, using the toilet, dressing, bathing, and walking across a room) and instrumental activities of daily living (for example, preparing meals, grocery shopping, making phone calls, taking medications, and managing money). The Health and Retirement Study asks respondents who report limitations in either type of activities whether anyone helps them and, if so, the relationship of the caregiver to them, the amount of care, and whether the care was paid for.

We calculated the number of monthly hours of informal care using the average number of days per week or month (depending on how it was reported by the respondent) and the average number of hours respondents reported receiving help from each caregiver in the previous month. Caregiving was classified as informal when the caregiver was a relative or an unpaid nonrelative not affiliated with a caregiving institution. All other care was classified as formal. In line with previous work,[1] we imposed a limit of sixteen hours of care per day for each caregiver, to account for eight hours of sleep.

Many respondents received care from more than one caregiver. For those, we summed the hours of care provided by all caregivers to calculate total monthly hours of care received. *Intensive informal care* was defined as more than 200 hours of informal care per month.

We began with descriptive analyses of both the prevalence and intensity of care received by study respondents and their relationship to their caregivers. We then estimated a logistic regression model of the likelihood of receiving intensive help for individuals with probable dementia who received at least some informal care. All analyses were weighted, and standard errors were adjusted for clustering within households.

## Limitations

The Health and Retirement Study is one of only a few nationally representative data sets with information on informal caregiving. However, the study's data have several limitations. Respondents provide caregiver information only for people who help them with activities of daily living and instrumental activities of daily living. There are a variety of other types of help, of course, including general supervision and assistance. Thus, this measure likely underestimates the extent of help received by older adults.

The Health and Retirement Study also contains limited information on caregivers, so we know little about the caregivers themselves or any consequences of their caregiving (with the exception of spouse caregivers, who are themselves respondents in the study). Additionally, the imputed cognition classifications applied to the study's respondents are subject to misclassification error. However, the diagnostic method has been previously validated against neuropathological findings,[6] and the imputation model's performance closely corresponds to follow-up assessments using data from the Aging, Demographics, and Memory Study.

## Study Results

We focused on a subsample of 8,106 community-dwelling respondents ages seventy and over. Of these, 2,573 reported having at least one limitation in an activity of daily living or an instrumental activity of daily living, 1,712 received at least some care (formal or informal) for such a limitation, and 1,647 had at least one informal caregiver. Of adults receiving care, those with probable dementia received 171 hours of informal care per month, [7] versus 89 and 66 hours for cognitively impaired and normal adults, respectively (Exhibit 2). Overall, 83 percent of the hours of care received were provided by informal (versus formal) caregivers. This was true for adults in all categories of cognition, although the percentage of informal care hours was slightly lower for adults with probable dementia than for other adults.

For adults with normal cognition, caregivers were primarily spouses (37 percent), followed by daughters (26 percent; Exhibit 3). These patterns were not uniform across categories of cognitive status. For adults with cognitive impairment but no dementia, about a quarter of caregivers were spouses, and for adults with probable dementia, about 16 percent were spouses.[8] Daughters step forward when spouses are unavailable: A third of the caregivers to adults with cognitive impairment but no dementia were daughters, as were 37.5 percent of caregivers to adults with probable dementia.

Even though a smaller proportion of caregivers to individuals with cognitive impairment or probable dementia were spouses, spouses who did help provided more hours of care than other caregivers did (Exhibit 4). Daughters provided more hours than sons; other relatives rivaled sons in the hours of help they provided.

The predicted probability of receiving intensive informal care (200 or more hours of informal care per month) among the subset of respondents with dementia was 0.45 for married respondents compared to 0.24 for unmarried respondents, holding other model

variables constant at their means (Exhibit 5). White adults were significantly less likely to receive intensive informal care than their black and Hispanic counterparts. Complete regression results are in online Appendix A-1.[9]

## Discussion

Consistent with other work, our results show that family members play an integral role in the provision of care for older adults with and without dementia. But who in particular adopts the role of caregiver varies by cognitive status. The primary caregivers for adults with normal cognition are spouses, but for adults with cognitive impairment or dementia, daughters are the most likely to provide informal care. Nonetheless, our results also show that when spouses do help, they provide more intensive care than do other relatives. In our multivariate models, we see further evidence of this: Married older adults with probable dementia receive more intensive informal care than their unmarried counterparts.

Our estimate of 5.5 million informal care recipients is lower than the 9 million care recipients reported by Spillman and coauthors.[4] Differences in the findings are likely due to several factors. First, Spillman and coauthors included individuals ages sixty-five and older, while we included those ages seventy and older. Second, Spillman and coauthors included individuals in supportive care settings. Finally, there were also small differences between the two sources of data related to the measures of activities of daily living and instrumental activities of daily living that were used to screen respondents for being at risk of needing care.

Using 2012 data from the Integrated Health Interview Series, Carrie Henning-Smith and Tetyana Shippee showed that nearly 60 percent of adults ages 40–65 believed that they were unlikely to need long-term services and supports in the future.[10] When asked who they expected would provide the care they would need, 73 percent of respondents believed that their family would provide this assistance.

While family members do provide help to those who need it, our findings highlight the future gaps expected in informal care availability for older adults living with probable dementia or cognitive impairment but no dementia, compared to cognitively normal older adults, and show which groups are at greatest risk. For instance, the fact that daughters are the most likely caregivers for individuals with dementia is alarming in light of shrinking family sizes and the growing numbers of women in the labor market: These changes suggest that in the future, this source of care for people with dementia may be less available.

In addition, the level of intensive care provided by spouses and members of minority groups to family members with dementia suggests that these groups may need targeted interventions to ensure that they are adequately trained and provided the necessary resources to care for loved ones without that care taking too much of a toll on their own health and well-being.

There are several possible explanations for our finding that minorities are more likely than whites to provide intensive care to family members with dementia. For example, there may be differences by race/ethnicity in the likelihood of coresiding with family members or in beliefs about obligations to provide care within the family. Alternatively, our finding may

suggest that members of disadvantaged groups are less able than members of advantaged ones to access formal care services and are forced to rely on family members for care. These questions could be examined in future work.

## Conclusion

We found that the numbers of US adults with probable dementia or cognitive impairment but no dementia who receive informal care are already high. Short of major technological breakthroughs, the need for care is only going to rise in the future as the population grows older. Future efforts to reform the US long-term services and supports system should include a focus on policies to supplement and support informal caregivers.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

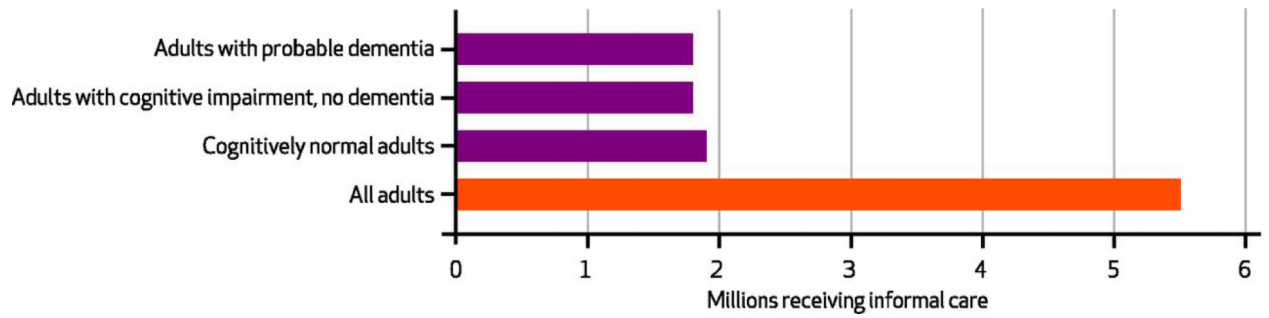
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## Notes

1. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013; 368(14):1326–34. [PubMed: 23550670]
2. Ory MG, Hoffman RR 3rd, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist*. 1999; 39(2): 177–86. [PubMed: 10224714]
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4. Spillman, BC.; Wolff, J.; Freedman, VA.; Kasper, JD. Informal caregiving for older Americans: an analysis of the 2011 National Health and Aging Trends Study [Internet]. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation; Washington (DC): Apr 1. 2014 Available from: <http://aspe.hhs.gov/daltcp/reports/2014/NHATS-IC.cfm> [2015 Aug 24]
5. We could not assess the total number of caregivers in the population because the Health and Retirement Study sample weights are for the care recipients, not the caregivers.
6. Plassman BL, Khachaturian AS, Townsend JJ, Ball MJ, Steffens DC, Leslie CE, et al. Comparison of clinical and neuropathologic diagnoses of Alzheimer's disease in 3 epidemiologic samples. *Alzheimers Dement*. 2006; 2(1):2–11. [PubMed: 19595851]
7. Because we summed hours across caregivers, if at least one caregiver provided information on care, respondents were retained in the analyses even if information was missing for some caregivers. This may result in our having underestimated the total hours of care.
8. Analyses were not adjusted for spouse's age or health, so this finding may be partly due to the older ages of couples in which one partner has probable dementia. Spouses of individuals with probable dementia may themselves be unhealthy and ill equipped to care for their partner, or they may already be deceased.
- 9.

To access the Appendix, click on the Appendix link in the box to the right of the article online.

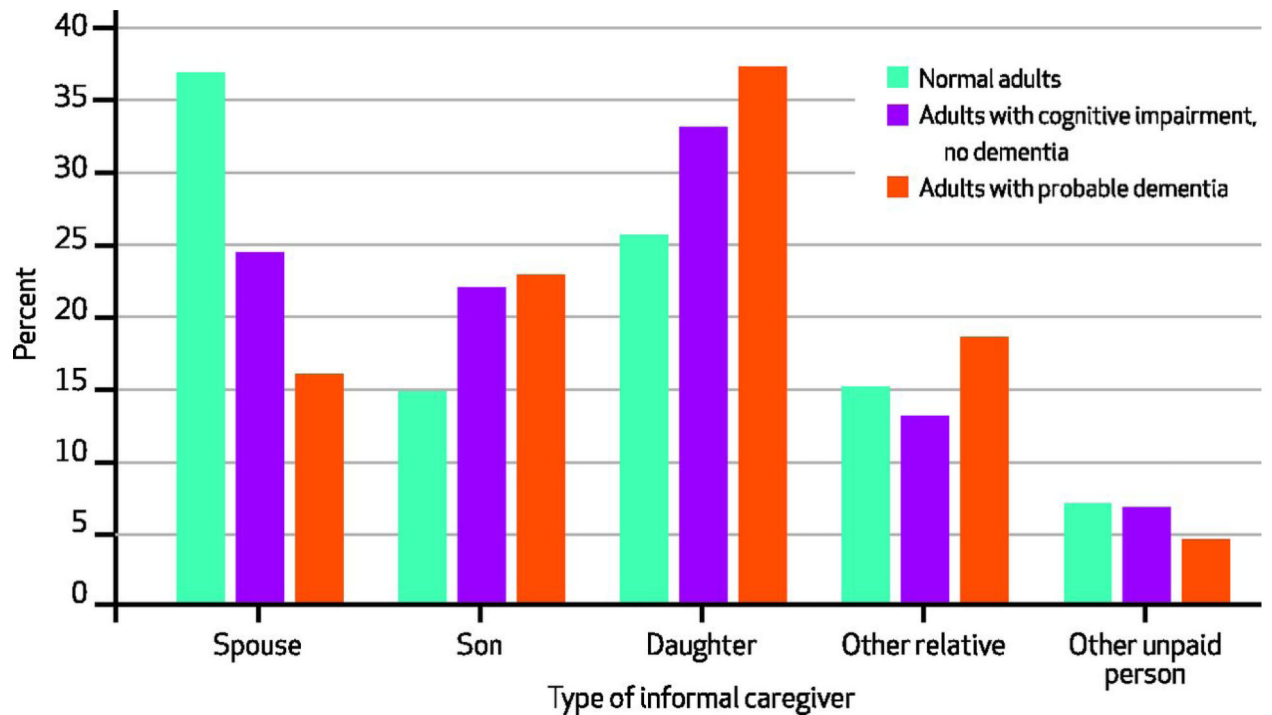
10. Henning-Smith CE, Shippee TP. Expectations about future use of long-term services and supports vary by current living arrangement. *Health Aff (Millwood)*. 2015; 34(1):39–47. [PubMed: 25561642]

**EXHIBIT 1.**

Number Of Community-Dwelling US Adults Ages 70 And Older Receiving Informal Care In The Past Month By Cognitive Status, 2010

SOURCE Authors' analysis of data from the 2010 Health and Retirement Study. NOTES

The data are weighted using survey weights to represent the noninstitutionalized US population in 2010. Care refers to help with activities of daily living or instrumental activities of daily living because of functional limitations.

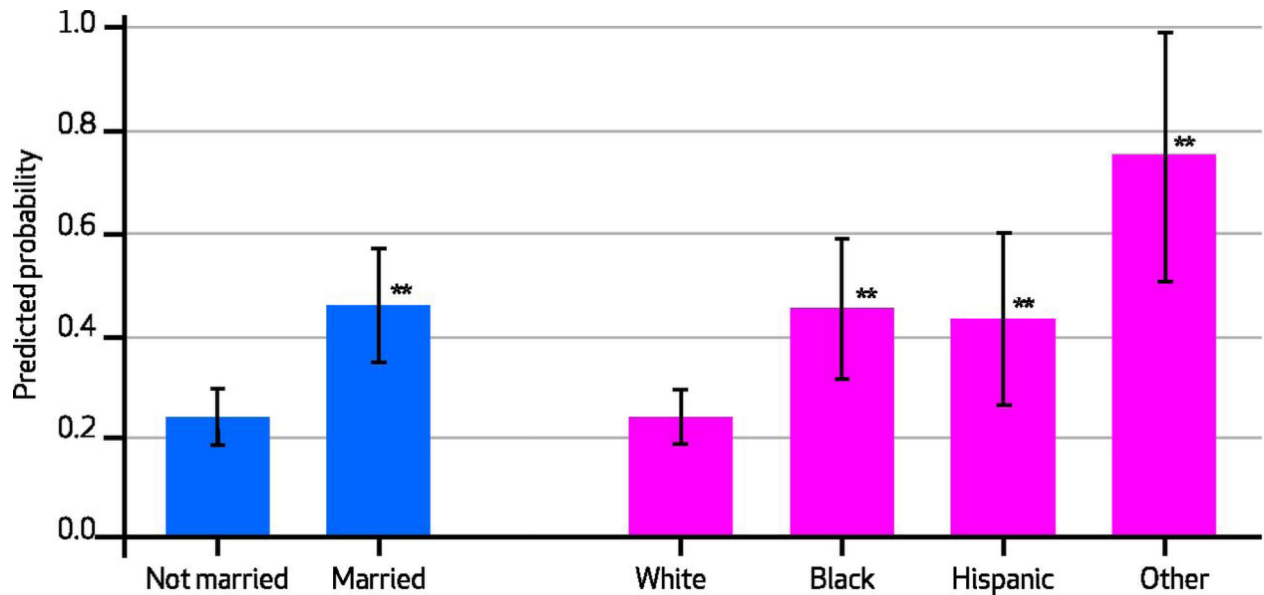
**EXHIBIT 3.**

The Relationship Of Community-Dwelling US Adults Ages 70 And Older Who Receive Informal Care To Informal Caregivers By Cognitive Status, 2010

SOURCE Authors' analysis of data from the 2010 Health and Retirement Study. NOTES

The data (from 2,769 informal caregivers who provided help in the past month) are weighted using survey weights to represent the noninstitutionalized US population in 2010. Care refers to help with activities of daily living or instrumental activities of daily living because of functional limitations.



**EXHIBIT 5.**

The Predicted Probability (With 95 Percent Confidence Intervals) Of Receiving Intensive Informal Care In The Past Month for Community-Dwelling US Adults Ages 70 And Older With Dementia Who Receive Informal Care, By Marital Status And Race/Ethnicity, 2010 SOURCE Authors' analysis of data from the 2010 Health and Retirement Study. NOTES The data (from 471 respondents with probable dementia who receive information care and for whom we have information on hours of care received as well as complete information for the model variables) are weighted using survey weights to represent the noninstitutionalized US population in 2010. Care refers to help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) because of functional limitations. *Intensive care* is defined as more than 200 hours of care per month across all caregivers. The model are adjusted for age in years, sex, race (non-Hispanic white, non-Hispanic black, Hispanic, or other) education (< high school degree, high school degree, some college, or college or more), household wealth in quintiles, number of children (0, 1, 2, or 3 or more), number of ADL functional limitations, number of IADL functional limitations, and number of chronic conditions. All model variables other than those displayed were held constant at their means. Nonmarried respondents were compared to married respondents; all racial/ethnic groups other than white were compared to white. \* $p < 0.10$  \*\* $p < 0.05$

**Exhibit 2****Prevalence And Intensity Of Informal Care Received By Community-Dwelling US Adults Ages 70 And Older In The Past Month By Cognitive Status, 2010**

	All adults	Normal adults	Adults with cognitive impairment but no dementia	Adults with probable dementia
Adults receiving informal care				
All adults <sup>a</sup>	19.9%	9.5%	32.9%	74.6%
Adults who report at least one ADL or IADL limitation <sup>b</sup>	62.4%	45.9%	66.8%	89.9%
Adults receiving formal or informal care <sup>c</sup>				
Total hours of informal care across all caregivers <sup>d</sup> (SD)	108.0 (159.9)	65.8 (107.6)	89.3 (136.2)	171.1 (204.0)
Share of total care hours that are informal	83%	87%	84%	78%
Average number of informal caregivers (SD)	1.6 (1.0)	1.4 (0.91)	1.5 (1.0)	1.8 (1.2)
Share of caregivers who are informal	87%	90%	87%	83%

SOURCE Authors' analysis of data from the 2010 Health and Retirement Study.

NOTES The data are weighted using survey weights to represent the noninstitutionalized US population in 2010. "Care" refers to help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) because of functional limitations. SD is standard deviation.

For some respondents, no caregiver provided information on hours of care; those respondents were excluded from the analyses. For other respondents, only some caregivers provided information about care. Those respondents were retained in the analyses, and as a result the hours of informal care may be underestimates.

<sup>a</sup>  
*n* = 8,106.

<sup>b</sup>  
*n* = 2,573.

<sup>c</sup>  
*n* = 1,712.

<sup>d</sup>  
*n* = 1, 558.

**Exhibit 4**

Hours Of Help Provided By Informal Caregivers In The Past Month To US Adults Ages 70 And Older By Cognitive Status, 2010

	Normal adults		Adults with cognitive impairment but no dementia		Adults with probable dementia	
Caregiver	Mean	SD	Mean	SD	Mean	SD
Spouse	66.2	(95.8)	105.1	(141.5)	180.3	(173.0)
Son	24.7	(41.1)	45.4	(74.3)	70.6	(119.1)
Daughter	51.4	(85.6)	51.6	(90.7)	97.2	(141.2)
Other relative	28.6	(59.2)	40.7	(88.7)	70.8	(114.5)
Other unpaid individual	23.6	(59.6)	20.0	(38.8)	81.0	(145.0)

SOURCE Authors' analysis of data from the 2010 Health and Retirement Study.

NOTES The data (from 2,565 informal caregivers with information on hours of help) are weighted using survey weights to represent the noninstitutionalized US population in 2010. "Care" refers to help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) because of functional limitations. SD is standard deviation.