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DO PEOPLE WITH DEMENTIA GET HELP MANAGING THEIR MONEY?

By Anek Belbase, Geoffrey T. Sanzenbacher, and Abigail Walters*

Introduction

One of the first signs that a person has dementia is difficulty with financial tasks. At first, it may just take longer to balance a checkbook or pay bills on time. Eventually, though, dementia erodes the capacity to carry out everyday transactions. So people with dementia need someone to help them manage their money – at first to avoid mistakes and later on to make sure their resources are not misused or abused. Since 5.5 million Americans ages 65 and over have dementia today, it is important to know whether they receive the assistance they need.1

An earlier brief provided some positive news: most people with dementia potentially have access to financial help, often from family.2 But due to data limitations, the study could not examine whether these informal caregivers actually did assist with financial management, and if so, whether it made a difference in financial well-being. After all, it is not clear whether the help offered by caregivers, who may lack full knowledge about their charges’ finances, would necessarily prove effective and, in rare cases, caregivers could turn out to be financial abusers.3 In these instances, people receiving “help” could end up worse off. This brief explores how many dementia sufferers have help and whether it improves their situation.4

The discussion is organized as follows. The first section briefly introduces the challenge that dementia poses for handling finances. The second section addresses whether those with dementia have help managing their finances. The third section presents results on whether the assistance appears to improve financial well-being. The final section concludes that the vast majority of individuals with dementia have help managing their money, mostly from family, and that the assistance appears to reduce financial hardship. However, social service organizations should keep their eyes out for the minority who do not have help in order to prevent their financial situation from deteriorating. This vigilance will be especially important in the future, as lower fertility rates and higher divorce rates may leave more individuals without family to provide help.

Dementia, Financial Ability, and Potential Help

As people age, the incidence of dementia increases dramatically, from about 3 percent for ages 70-74 to roughly 30 percent for ages 85 and over.5 Dementia
impairs a wide range of cognitive functions, but the ability to manage finances is one of the first capacities to suffer. About 80 percent of those with dementia are incapable of managing their money. Help could come from formal sources like Social Security’s Representative Payee Program, which allows a third party to receive and manage someone’s benefits, or informal sources like a spouse or an adult child. A recent report, using the Health and Retirement Study (HRS), found that the vast majority of people with dementia do not have a Representative Payee but do have access to other potential sources of help, typically family members (see Table 1). This brief uses a different dataset – the National Health and Aging Trends Study (NHATS) – to find out whether individuals with dementia actually receive help managing their money and whether it improves their financial well-being compared to those who do not receive assistance.

The NHATS data are well suited for addressing the objectives of this analysis. It is a nationally representative longitudinal survey of Medicare beneficiaries ages 65 and older. Since 2011, this survey has conducted annual, in-person interviews to capture trends in late-life functioning. The dataset provides a comprehensive view of how older adults adapt to the changes associated with aging by asking participants about their economic well-being, difficulty carrying out daily activities, and help or accommodations made to carry out those activities. This analysis uses NHATS data from 2011-2014, which provide a total sample of 8,245 people. Starting with this sample, the study first identifies people with dementia and then examines whether they received help managing their finances.

Because the NHATS – like most publicly available datasets – does not directly identify respondents with dementia, this study relies on an algorithm developed for previous research. The algorithm uses self-reported diagnoses of dementia, results of dementia screening interviews, and cognitive test scores to classify people as either having “no dementia,” “possible dementia,” or “probable dementia.” Starting with this basic classification, the study then takes advantage of the longitudinal nature of the NHATS panel. First, those classified as having probable dementia who later improve are dropped from the sample because we are interested in the degenerative forms of the disease. Second, since financial capacity is impaired more as dementia progresses, the study classifies respondents as having “established dementia” if they had probable dementia for three or four years within the sample. Figure 1 shows that the share of the sample with established dementia generally increases with the age of the sample (the slight decline at ages 90 and over is likely due to fewer observations).

### Table 1. Available or Potential Assistance, by Cognition Status

<table>
<thead>
<tr>
<th>Percentage with:</th>
<th>Mild cognitive impairment</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Representative Payee</td>
<td>2%</td>
<td>9%</td>
</tr>
<tr>
<td>Nursing home care</td>
<td>3</td>
<td>29</td>
</tr>
<tr>
<td>Non-impaired spouse</td>
<td>37</td>
<td>29</td>
</tr>
<tr>
<td>Resident child</td>
<td>17</td>
<td>23</td>
</tr>
<tr>
<td>Help from a child</td>
<td>12</td>
<td>37</td>
</tr>
<tr>
<td>Power of attorney</td>
<td>63</td>
<td>63</td>
</tr>
<tr>
<td><strong>Any form of assistance</strong></td>
<td><strong>85</strong></td>
<td><strong>95</strong></td>
</tr>
</tbody>
</table>

Note: Some individuals have more than one potential source of help.

### Do People with Dementia Get Help Managing Money?

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### Figure 1. Percentage of Older Individuals with Established Dementia, by Age

Source: Authors’ calculations from the Johns Hopkins Bloomberg School of Public Health, National Health and Aging Trends Study (NHATS) (2011-2014).
To determine whether those with established dementia have help with their finances, the analysis uses data on how simple money matters were handled in the past month. Simple money matters are common tasks, such as writing checks, monitoring bank balances, and making deposits or withdrawals. Nearly 87 percent of those with established dementia have help with these simple activities at least some of the time. Figure 2 suggests that this help most often comes from family members, with spouses and children providing almost 90 percent of the assistance. Like other kinds of care, daughters play an outsized role compared to sons.

The finding that most people have assistance with financial management is largely consistent with the results from Table 1 and suggests that, in most cases, informal helpers provide the assistance. But is this help effective?

Is defined as whether respondents skipped meals in the past month because they did not have enough money. Financial hardship is measured by whether respondents reported instances of not having enough to pay the rent/mortgage, utility bills, or medical/ prescription drug bills in the past year. These measures of financial hardship are then combined into a single metric equal to one if the individual has any of these problems and zero otherwise. About 5.5 percent of those with established dementia have at least one of these measures of serious financial hardship compared to 4.0 percent for those without it. The key question is whether, for those with established dementia, this number is lower than for those who have assistance with financial management.

While a simple tabulation could answer that question, it could also be misleading. For example, if those with access to financial management assistance are more educated, then they may be less likely to experience financial hardship, but not because of the help they are receiving. In this case, the benefit of receiving help would be overstated. Or, if people who receive help with financial management also have many other issues that require assistance, the effect of help could be understated since they were so much worse off initially.

To control for the effect of other factors that could explain any correlation between financial assistance and well-being, the brief uses a regression analysis. The two variables of interest are: 1) having established dementia; and 2) having both established dementia and help with finances. The effect of the first variable tells how much dementia hurts financial well-being, and the effect of the second variable tells how much having help reduces that initial harm.

The regression controls for demographic factors like education, age, gender, race/ethnicity, residence in a metro area, and marital status. Other controls are indicators of physical health, which include the number of negative health conditions and the number of basic activities with which people need assistance. The activity measures are Activities of Daily Living (ADLs, e.g., dressing) and Instrumental Activities of Daily Living (IADLs, e.g., cooking). Finally, the regression controls for income, in case high-income individuals are more likely to have assistance and thus appear better off.

Figure 2. Relationship of Financial Caregiver to Individual with Established Dementia

Source: Authors’ calculations from NHATS (2011-2014).
Figure 3 presents the results for selected variables. A positive effect indicates the variable is associated with a higher likelihood of having financial difficulties. The results show that those with established dementia are 7 percentage points more likely to have difficulties, but that receiving assistance with financial management offsets this damage, reducing the likelihood of having such difficulties by nearly 10 percentage points. In other words, individuals with dementia who receive financial assistance are much better off than dementia sufferers without assistance. And, strikingly, having financial assistance completely eliminates the negative effect of dementia on financial hardship.

The results for the other variables are consistent with expectations. Those who need help with many ADLs, have many negative health conditions, and live in metro areas are more likely to have difficulties. For example, an individual with two ADLs (the average for those with established dementia) has a 1.6-percentage-point higher probability of having financial difficulties compared to someone with no such limitations. On the other hand, those with higher incomes are slightly less likely to have problems.

Conclusion

The odds of developing dementia increase exponentially with age, a particularly serious concern given the aging of the U.S. population. Since dementia severely erodes the capacity to manage one’s finances, these individuals will need help. This brief addressed whether they are likely to have help and, if so, whether it actually reduces financial hardship. The results present a somewhat optimistic picture. Roughly 87 percent of those with established dementia received help managing their money and those with help appear to be as well off financially as those without dementia.

However, 13 percent of older people with established dementia did not get help and were much more likely to struggle with their finances. And it is possible that this number will rise in the future. After all, today’s elderly are the parents of Baby Boomers and so have many children to help – future generations’ have fewer kids. This fact, coupled with higher divorce rates, means that one major source of care will be less available to the future elderly. Going forward, social service organizations should work to identify those without financial assistance to ensure we do not have a growing population of individuals with dementia who suffer financial hardship.
Endnotes

1 Alzheimer's Association (2017).


3 Acierno et al. (2010).

4 The brief is based on a recent study (Belbase and Sanzenbacher 2017a).

5 Belbase and Sanzenbacher (2017b).

6 Marson et al. (2009).

7 The HRS has data limitations that make it difficult to determine whether people actually receive help. For example, individuals who indicate they do not need help are not asked whether they receive it. Because people may be slow to realize they are in need of help (Hsu and Willis, 2013) they may indicate that they do not need assistance even if they are actually receiving it.

8 The 2015 NHATS data were excluded from this analysis, because a large portion of the sample was refreshed that year, and this study relies on longitudinal trends to classify people with early- or late-stage dementia.


10 The survey also asks about more complicated matters, like withdrawals from retirement accounts. However, a smaller fraction of the sample conducts such transactions and, among those who do, the same proportion of individuals receive help as for simple money matters. For more detail, see Belbase and Sanzenbacher (2017a).

11 One potential source of the difference between Table 1 and Figure 1 (95 percent versus 87 percent with assistance) is that the NHATS does not have data on Representative Payee use.

12 For full results, see the Appendix.
References


APPENDIX
<table>
<thead>
<tr>
<th>Variable</th>
<th>Marginal effect</th>
<th>Standard error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Established dementia</td>
<td>0.071*</td>
<td>0.037</td>
</tr>
<tr>
<td>Established dementia and help</td>
<td>-0.099**</td>
<td>0.039</td>
</tr>
<tr>
<td>College education</td>
<td>-0.009</td>
<td>0.006</td>
</tr>
<tr>
<td>Lives in a metro area</td>
<td>0.016**</td>
<td>0.007</td>
</tr>
<tr>
<td>Two ADLS</td>
<td>0.016**</td>
<td>0.004</td>
</tr>
<tr>
<td>Two IADLS</td>
<td>0.010</td>
<td>0.004</td>
</tr>
<tr>
<td>Two health conditions</td>
<td>0.018**</td>
<td>0.002</td>
</tr>
<tr>
<td>10-percent increase in income</td>
<td>-0.003***</td>
<td>0.004</td>
</tr>
<tr>
<td>Early dementia</td>
<td>0.006</td>
<td>0.014</td>
</tr>
<tr>
<td>Early dementia and help</td>
<td>0.025</td>
<td>0.022</td>
</tr>
<tr>
<td>Financial help</td>
<td>0.009</td>
<td>0.007</td>
</tr>
<tr>
<td>Male</td>
<td>-0.004</td>
<td>0.006</td>
</tr>
<tr>
<td>Black</td>
<td>0.060***</td>
<td>0.009</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.061***</td>
<td>0.019</td>
</tr>
<tr>
<td>Other</td>
<td>0.055**</td>
<td>0.027</td>
</tr>
<tr>
<td>Couple</td>
<td>-0.009</td>
<td>0.011</td>
</tr>
<tr>
<td>Widowed</td>
<td>-0.011</td>
<td>0.011</td>
</tr>
<tr>
<td>Ages 70-74</td>
<td>0.005</td>
<td>0.011</td>
</tr>
<tr>
<td>Ages 75-79</td>
<td>-0.028**</td>
<td>0.011</td>
</tr>
<tr>
<td>Ages 80-84</td>
<td>-0.040***</td>
<td>0.011</td>
</tr>
<tr>
<td>Ages 85-89</td>
<td>-0.050***</td>
<td>0.012</td>
</tr>
<tr>
<td>Ages 90+</td>
<td>-0.062***</td>
<td>0.013</td>
</tr>
<tr>
<td>Respondent has proxy</td>
<td>-0.044***</td>
<td>0.014</td>
</tr>
<tr>
<td>Constant</td>
<td>0.340***</td>
<td>0.040</td>
</tr>
</tbody>
</table>

Number of observations  8,024
R-squared               6.4%

Note: *p<0.10, ** p<0.05, ***p<.01.
Source: Authors’ calculations from the NHATS (2012-2014).
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Contact Information

Center for Retirement Research
Boston College
Hovey House
140 Commonwealth Avenue
Chestnut Hill, MA 02467-3808
Phone: (617) 552-1762
Fax: (617) 552-0191
E-mail: crr@bc.edu
Website: http://crr.bc.edu

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