Dementia, Help with Financial Management, and Financial Well-Being

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To prevent financial exploitation, Social Security allows beneficiaries who cannot manage their own benefit to relinquish control to a representative payee. Once designated, a representative payee is required to decide how to spend a beneficiary's Social Security income and to keep records of that spending. Most of the Representative Payee Program's 5.5 million participants are children or disabled adults.[1] However, just over 500,000 retirement beneficiaries have a representative payee as well. While this may sound like a large number of retirees with payees to some, it means just 1.5 percent of retirees have a payee despite the fact that around 10 percent have dementia.[2] This seeming imbalance has led some observers to suggest that SSA should cover more retirees under the Representative Payee Program.[3]

However, dementia poses a unique challenge to the Representative Payee Program, since some individuals with dementia are still capable of receiving and managing their own benefits, while others are not.[4] Simply assuming that those with dementia need a payee risks taking away someone's independence prematurely. The difference between needing a payee or not often comes down to the quality of a person's informal care network.[5] Although almost all people with common forms of dementia will eventually lose the ability to manage their finances, initially, caregivers can make decisions jointly before permanently "taking the keys away" as impairment becomes more severe. Therefore, to evaluate how well the Representative Payee Program is serving the population in need, SSA needs to understand informal care networks.

Belbase and Sanzenbacher (2016), using the HRS linked to Social Security administrative data, find that most people have some other source of assistance available. Over 95 percent of beneficiaries with dementia either have a representative payee, have a non-impaired spouse or child, have given someone power of attorney, or live in a nursing home where they often do not need to manage their finances. Thus, very few retirees are in the vulnerable position of living in the community without some sort of assistance available. But while this existing research suggests that most retirees with dementia potentially have access to sources of help, because of data limitations it is not known whether these helpers actually assist in managing finances and, if so, whether the assistance prevents misuse or abuse of financial resources.

[1] Over 3 million SSI recipients also have a representative payee.
[2] Anguelov, Ravida, and Weathers II (2015) and Herbert et al., (2013).
[3] For example, a 2010 audit by the Office of the Inspector General found retirees over age 85 in need of a payee, and some experts have argued that the process that field offices use to determine financial capacity tends to err on the side of finding someone capable rather than incapable (National Academy of Sciences, 2016).
[4] See Marson et al. (2009).
[5] See Arias (2013) and Berry, Apesoa-Varano, and Gomez (2015).

The Current Study

To fill this gap in the literature, this study uses data on more than 7,000 Medicare enrollees participating in the *National Health and Aging Trends Study* (NHATS) to examine the role of informal helpers in managing money for people with dementia. Since 2011, the NHATS 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 capturing variables on economic and psychological well-being, difficulty carrying out daily activities, and help or accommodations made to carry out those activities.

To identify respondents with cognitive impairment and dementia, this study relies on the methodology of Kasper et al. (2013). Recognizing that the NHATS (like most publicly available microeconomic datasets) does not contain medical diagnoses of dementia, Kasper et al. (2013) create an algorithm using the self-reported diagnosis of dementia, results of a dementia screening interview, and cognitive test scores to classify people as either having "no dementia," "possible dementia," or "probable dementia." This paper takes an extra step and identifies people as having "established dementia" (and a high likelihood of needing financial assistance), based on the frequency with which they are assigned "probable dementia" during their time in the NHATS.

Once an individual is identified as having "established dementia," this paper uses detailed questions on the help that caregivers provide to examine whether individuals in a retiree's caregiving network provide assistance with simple financial matters like bill paying and with more complex money matters like managing retirement accounts. The paper also examines how the help received from informal caregivers affects the financial and psychological well-being of retirees with dementia.

Results

The paper has four key findings. First, over 85 percent of those with established dementia are receiving help with both simple and complex money matters. Second, as people transition from normal cognition to dementia, any source of financial assistance shifts from spouses to children – often daughters. Third, those with established dementia who receive help face fewer issues paying for food, rent, utilities, and medical expenses and also experience less anxiety compared to those with established dementia who manage their finances without help. Indeed, those with established dementia and a source of financial management assistance appear as well off along these dimensions as those without any dementia. Fourth, while this study does not definitively establish a causal link between help with financial management and well-being, the beneficial effect of help with financial management persists even after controlling for a number of other factors that could explain the correlation (such as income, education, and health).

These findings offer a mostly positive view of how financial management is working for those with established dementia. Although earlier research showed most people do not use a representative payee, most do seem to have help available both for their simple banking matters and more complex money management. Perhaps just as importantly, the study suggests that those with established dementia and help available are faring as well as those without any cognitive impairment. This finding should lessen the concern that a high proportion of caregivers are taking advantage of their charges. While informal caregivers can and do sometimes financially exploit beneficiaries, this study suggests that, on average, receiving help managing finances is related to higher well-being among people with late-stage dementia relative to those not receiving help.

Still, some reason for concern exists. The 15 percent of those with established dementia and without help appear significantly worse off. The paper finds that these individuals are nearly twice as likely as those without dementia to have trouble paying for food, rent, utilities, and medicine. Individuals who have been divorced or widowed, or whose spouses have become impaired, are especially vulnerable to being in this situation, especially if their children do not live nearby. It may be helpful for policymakers and social workers to be aware of these individuals and improve targeted outreach to them to ensure Social Security benefits are properly managed.

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