

ARE MANY RETIREES WITH DEMENTIA LACKING HELP?

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Introduction

Many older individuals with cognitive impairment, including the vast majority of people with dementia, need help managing their finances. For retirees receiving Social Security benefits, the Representative Payee Program can serve as one source of this help. In the Representative Payee Program, a retiree's benefit is sent to another person (often a relative) who spends it on the retiree's behalf and submits records to Social Security documenting that the expenditures were in the beneficiary's best interest. But the program seems to be seldom used by those with dementia: of those 65 and older, over 10 percent have dementia, but just 1.5 percent have a payee. This lack of participation may not be a problem as long as the retiree has some other source of help.

This *brief*—based on a recent paper—uses data from the *Health and Retirement Study* (HRS) linked to administrative Social Security records to first document what share of retirees with mild cognitive impairment or dementia use the Representative Payee Program.¹ Given that few use the program, the *brief* then turns to the question of what they do instead.

The options considered include help from an informal caregiver (e.g., a non-impaired spouse or child), from the staff of a nursing home, or from a Power of Attorney they may have assigned. Once these sources of help are identified, the *brief* then focuses on the types of people who seem to lack any observed form of aid in order to help policymakers and community-based organizations better identify the most vulnerable individuals.

The discussion proceeds as follows. The first section estimates the share of retirees with mild cognitive impairment and dementia. The second section documents what sources of help people have and what share of retirees with impairment are lacking it. The third section identifies groups who are especially likely to have no observed source of help available. The final section concludes that while few retirees with dementia use the Representative Payee Program, the vast majority have some potential source of assistance. Groups vulnerable to having no help available include those with less education, minorities, and individuals living in densely populated areas.

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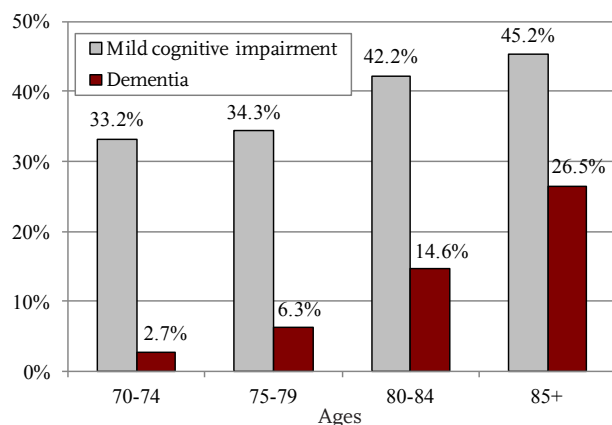
How Many Are Impaired?

To construct the sample of interest – retirees with cognitive impairment – the HRS is restricted to those ages 70 and over who receive a Social Security retirement benefit.² To identify those with cognitive impairment, the sample is divided into three groups, those with: 1) no observed cognitive impairment; 2) mild cognitive impairment; and 3) dementia.

Because the HRS does not directly ask about dementia, it is necessary to rely on an imputation method developed in another study to create these groups.³ That methodology starts with a subsample of the HRS that *did* have a direct measure of dementia – a sample given detailed cognitive assessments during the Aging, Demographics, and Memory Study. These sample members were either diagnosed as having no impairment, mild cognitive impairment, or dementia. The characteristics of these diagnosed subsample members were then used to predict whether members of the full sample had these conditions.⁴

Of course, this indirect method may fail to identify some people who have mild cognitive impairment but who do not have the characteristics identified that are predictive of this condition. For this reason, the study also classifies any individuals as having mild cognitive impairment if they: 1) cannot remember the correct date; 2) failed in two attempts counting backwards from 86; 3) failed in two attempts counting backwards from 20; or 4) remembered at most one word from a list of ten words. As one would expect, the results show that mild cognitive impairment and dementia become more common with age (see Figure 1).

FIGURE 1. PERCENTAGE OF HOUSEHOLDS AGES 70+ WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA



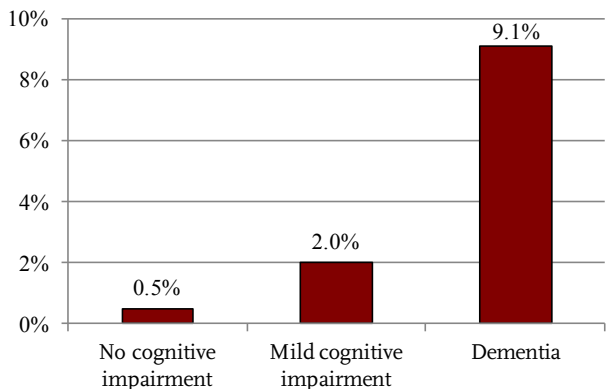
Sources: Authors' calculations from the *Health and Retirement Study* (HRS), 1992-2010; and Hurd et al. (2013).

The onset of cognitive decline often leads to a decline in the ability to manage one's finances. About 5 percent of those without any impairment need help managing their finances, increasing to 18 percent for those with mild impairment and ultimately 80 percent for those with dementia.⁵ For those who need help, the question is whether or not they have it.

Do the Impaired Have Help?

Determining which retirees with cognitive impairment have access to financial assistance is based on two measures of assistance. The first is access to a representative payee. Individuals with a payee are identified using the restricted *Respondent Cross-Year Benefits* file, which records payee use and is linked to the core HRS.⁶ Figure 2 shows that as cognitive impairment worsens, the use of a Representative Payee increases dramatically. Still, even for those with dementia, payee use is below 10 percent.

FIGURE 2. PERCENTAGE OF HOUSEHOLDS AGES 70+ USING A PAYEE, BY COGNITIVE IMPAIRMENT STATUS



Sources: Authors' calculations from 1992-2010 HRS; Social Security Cross-Year Benefits Records; and Hurd et al. (2013).

Given that payee use is uncommon, a second more inclusive set of possible sources of financial assistance is considered. The first source is a spouse who has no sign of mild cognitive impairment or dementia. The second source is children who are either living with their parent or are helping them with either Activities of Daily Living or Instrumental Activities of Daily Living. The third source of help is residence in nursing homes. Financial management may be easier for those in a nursing home since, in

some cases, their benefit may be applied directly to the stay. Fraud may also be less likely if individuals are not exposed to the wider community. The final source considered is the designation of power of attorney. With respect to power of attorney, our approach is admittedly imperfect. The HRS does not ask its full sample specifically about financial powers of attorney.⁷ Instead, it asks about whether the individual has designated a durable power of attorney in the context of health. The assumption is that a person serving as a power of attorney for health is likely also available to provide other assistance. Although none of these sources of help is sure to prevent financial fraud or abuse (for example, children themselves sometimes commit abuse),⁸ people without any of these forms of help are likely financially vulnerable.

Fortunately, most individuals do have some help (see Table 1). Eighty-five percent of those with mild cognitive impairment have at least one form of help, and 95 percent of those with dementia have help. As people transition from mild cognitive impairment to dementia, unimpaired spouses become less common but children appear to step into the breach.

Given that impaired individuals without assistance are vulnerable, the question is who they are.

Who Does Not Have Help?

To determine the characteristics of those without any source of financial assistance, the analysis used the HRS to identify several likely correlates of lacking assistance. The first variable reflects the extent to which the individual is isolated (not having a non-impaired spouse and not having children within 10 miles). A

TABLE 1. AVAILABLE ASSISTANCE, BY COGNITION STATUS

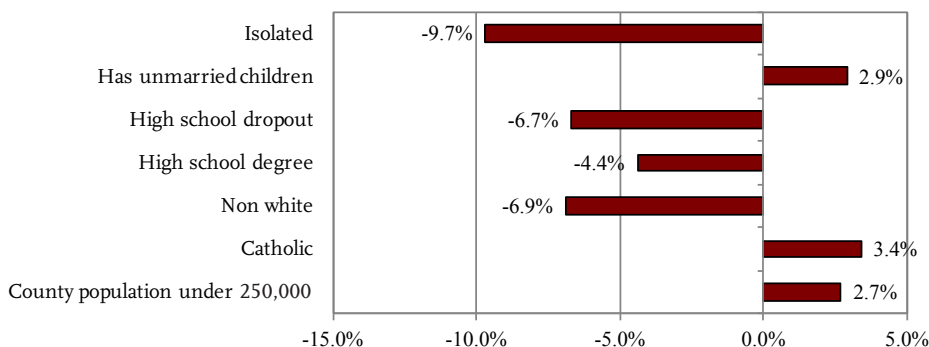
| Percentage with: | Mild cognitive impairment | Dementia |
|-------------------------------|---------------------------|-------------|
| Representative payee | 2.0% | 9.1% |
| Nursing home care | 3.2 | 28.7 |
| Non-impaired spouse | 37.2 | 29.1 |
| Resident child | 17.3 | 23.4 |
| Help from a child | 12.2 | 36.6 |
| Power of attorney | 62.9 | 63.2 |
| Any form of assistance | 85.0 | 95.1 |
| Number of observations | 1,756 | 492 |

Sources: Authors' calculation from 1992-2010 HRS; Social Security Cross-Year Benefits Records; and Hurd et al. (2013).

retiree's children's marital status is included since single children may be more able to help. Other variables include the retiree's education, with separate variables for status as a dropout or high school graduate (with "at least some college" as the base case). Race and ethnicity is controlled for with an indicator for whether the person is non-white or Hispanic. Finally, the analysis controls for the strength of an individual's community with indicators for affiliation with a Catholic Church and residence in a county with fewer than 250,000 people.⁹

Figure 3 shows the effect of these variables on the probability of having at least one form of assistance (a negative effect indicates people with that characteristic were less likely to have help).¹⁰ The results

FIGURE 3. ESTIMATED EFFECT OF SELECT VARIABLES ON PROBABILITY OF HAVING SOME FORM OF HELP FOR THOSE WITH MILD COGNITIVE IMPAIRMENT OR DEMENTIA



Note: All effects are statistically significant at least at the 10-percent level. Full results in Appendix.

Sources: Authors' calculations from 1992-2010 HRS; Social Security Cross-Year Benefits Records; and Hurd et al. (2013).

show that people who are isolated from family, less educated, and non-white are less likely to have help. In other words, those who are economically vulnerable in the traditional sense are also more likely to have little outside help and be vulnerable to financial mismanagement. Having a strong community, as indicated by involvement with a Catholic Church or residence in a small county, is associated with being more likely to have help.

Conclusion

Retirees with cognitive impairment and especially dementia need help managing their finances. Without help, they are vulnerable to financial fraud, abuse, or mismanagement. So, at a first glance, it is concerning that only 9 percent of retirees with dementia have a Representative Payee. After all, this program helps people manage what, for many, is their primary source of income: their Social Security benefit.

Fortunately, this analysis shows that most people without a payee have some other source of assistance available. These arrangements may be preferable to having a payee because they allow individuals to maintain some autonomy for as long as possible. Still, social service organizations should recognize that people who are vulnerable in other ways – for example because they have little education or are isolated from family – may also lack help managing their money.

Endnotes

- 1 Belbase and Sanzenbacher (2016).
- 2 Workers who have received non-retirement Social Security income, like disability or SSI, are excluded. In the analysis, one observation per person is used, either their last year in the sample or their observation from Wave 10 of the HRS. For more detail on the sample, see the full paper.
- 3 Hurd et al. (2013). In the most recent wave, the HRS did add a question on Alzheimer's.
- 4 In practice, this prediction was accomplished in two steps. First, ordered probit models were run using the subsample. In this regression, the independent variables were available in the full sample, and the dependent variable was no impairment, mild cognitive impairment, or dementia. The second step used the coefficients from the regression to form predictions for the full sample.
- 5 Marson et al. (2009).
- 6 Retirees are said to have a payee if they have a non-missing value for the "Custody Code" of their payee (e.g., spouse, natural or adopted child or stepchild, or non-profit non-mental institution, etc.).
- 7 A new experimental module does ask about financial power of attorney, but it was asked to only a subset of the population and the number of individuals in our sample who were asked the question is very small.
- 8 Acierno et al. (2010).
- 9 Affiliation with a Catholic church was included as a proxy for having access to social services. Other religions were tested, but in general the sample sizes were too small to yield a significant result.
- 10 Other controls were included in the regression but are not shown in Figure 3. These include the individual's history of being divorced or widowed, purchase of long-term care insurance, Social Security Primary Insurance Amount, gender, and region of residence. For full results, see the Appendix.

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APPENDIX

 APPENDIX TABLE 1. MARGINAL EFFECTS FOR SOME ASSISTANCE WITH FINANCIAL MANAGEMENT

| Variable | Coefficient |
|----------------------------------|-----------------------|
| Isolated | -0.097 *** (0.025) |
| Has unmarried children | 0.029 * (0.016) |
| High school dropout | -0.067 *** (0.026) |
| High school degree | -0.044 ** (0.021) |
| Non white | -0.069 *** (0.020) |
| Catholic | 0.034 ** (0.016) |
| County population under 250,000 | 0.027 * (0.015) |
| Age | 0.005 *** (0.001) |
| History of divorce/being widowed | -0.027 (0.027) |
| Has children | 0.002 (0.033) |
| Long-term care insurance | -0.028 (0.024) |
| Social Security PIA | -0.000 (0.000) |
| Male | -0.002 (0.016) |
| Midwest | -0.022 (0.025) |
| South | -0.010 (0.023) |
| West | 0.023 (0.024) |
| Number of observations | 2,615 |
| R-squared | 0.038 |

Notes: Statistically significant at 10-percent (*), 5-percent (**), or 1-percent level (***). Significance is calculated using robust standard errors, which are reported in parentheses.
 Source: Authors' calculations from 1992-2010 HRS.

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