

AWARD NUMBER: W81XWH-16-1-0746

TITLE: Effects of Alzheimer's Disease in the Prediagnosis Period on Financial Outcomes

PRINCIPAL INVESTIGATOR: Carole Roan Gresenz

CONTRACTING ORGANIZATION: RAND Corporation  
Seattle, WA 98095

REPORT DATE: DECEMBER 2019

TYPE OF REPORT: Final Report

PREPARED FOR: U.S. Army Medical Research and Development Command  
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release; Distribution Unlimited

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# REPORT DOCUMENTATION PAGE

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<b>1. REPORT DATE</b> Dec 2019			<b>2. REPORT TYPE</b> Final		<b>3. DATES COVERED</b> 30 Sep 2016 – 29 Sept 2019	
<b>4. TITLE AND SUBTITLE</b> Effects of Alzheimer's Disease in the Prediagnosis Period on Financial Outcomes					<b>5a. CONTRACT NUMBER</b> W81XWH-16-1-0746	
					<b>5b. GRANT NUMBER</b>	
					<b>5c. PROGRAM ELEMENT NUMBER</b>	
<b>6. AUTHOR(S)</b> Carole Roan Gresenz  E-Mail: crg70@georgetown.edu					<b>5d. PROJECT NUMBER</b>	
					<b>5e. TASK NUMBER</b>	
					<b>5f. WORK UNIT NUMBER</b>	
<b>7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)</b>  RAND Corporation, The 1776 Main St Santa Monica, CA 90401-3297					<b>8. PERFORMING ORGANIZATION REPORT NUMBER</b>	
<b>9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)</b>  U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012					<b>10. SPONSOR/MONITOR'S ACRONYM(S)</b>	
					<b>11. SPONSOR/MONITOR'S REPORT NUMBER(S)</b>	
<b>12. DISTRIBUTION / AVAILABILITY STATEMENT</b>  Approved for Public Release; Distribution Unlimited						
<b>13. SUPPLEMENTARY NOTES</b>						
<b>14. ABSTRACT</b>  The goal of this research is to understand how Alzheimer's Disease (AD)—before it is diagnosable using currently availability tools—affects the financial well-being of the individuals and families of those it afflicts. We conduct analyses of the Health and Retirement Study (HRS) data linked to Medicare claims data. The HRS includes longitudinal information on financial outcomes for a large panel of U.S. adults over age 50. Linking the HRS to Medicare claims data enables us to identify individuals who were diagnosed with AD by a physician and their date of diagnosis, so that we can look backward over time at the vulnerable period prior to diagnosis. In Year 1 of our project, we constructed the merged data; derived key dependent and independent variables and calculated descriptive statistics. In Year 2, we performed analyses of the effect of AD on financial outcomes and drafted our first paper. In Year 3, completed our analyses and disseminated our results.						
<b>15. SUBJECT TERMS</b> Alzheimer's Disease, dementia, assets, savings, wealth, debt, financial outcomes						
<b>16. SECURITY CLASSIFICATION OF:</b>				<b>17. LIMITATION OF ABSTRACT</b>	<b>18. NUMBER OF PAGES</b>	<b>19a. NAME OF RESPONSIBLE PERSON</b>
<b>a. REPORT</b>	<b>b. ABSTRACT</b>	<b>c. THIS PAGE</b>	<b>19b. TELEPHONE NUMBER</b> (include area code)			
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## Table of Contents

	<b>Page</b>
<b>1. Introduction.....</b>	<b>4</b>
<b>2. Keywords.....</b>	<b>4</b>
<b>3. Accomplishments.....</b>	<b>4</b>
<b>4. Impact.....</b>	<b>8</b>
<b>5. Changes/Problems.....</b>	<b>10</b>
<b>6. Products.....</b>	<b>11</b>
<b>7. Participants &amp; Other Collaborating Organizations.....</b>	<b>12</b>
<b>8. Special Reporting Requirements.....</b>	<b>15</b>
<b>9. Quad Chart.....</b>	<b>16</b>
<b>10. Appendices</b>	

## 1. INTRODUCTION

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Alzheimer’s Disease (AD) affects an estimated 5.3 million people in the U.S. and tens of millions of people worldwide, exacting substantial human and monetary costs. Existing tools for diagnosing AD lead to diagnoses that typically occur after the onset of severe symptoms. However, significant limitations and rapid declines in financial capacity occur among patients with early stage AD, years before the disease is diagnosable. Some argue that financial decision-making deficits are among the first functional changes in people with AD. But, burgeoning limitations in financial capacity are unlikely to be fully appreciated or recognized by individuals and their families prior to diagnosis, and may therefore result in consequential effects on household financial outcomes such as spending, debt, and susceptibility to financial exploitation. Thus, the time period before AD is diagnosable represents a uniquely vulnerable period for individuals and households. The extent to which AD in its early stages contributes to adverse financial outcomes among those afflicted has not been known. We hypothesized that early stage AD, during the period before it is diagnosable, negatively affects household financial outcomes. We further hypothesized that the effects of AD during the period before it is diagnosable on household financial outcomes are more consequential when the financial head of household is afflicted as opposed to a spouse or partner of the financial household head. The goal of this research was to understand how early stage AD—before it is diagnosable using currently availability tools—affects the financial well-being of the individuals and families of those it afflicts. We conducted analyses of the Health and Retirement Study (HRS) data linked to Medicare claims data. The HRS includes rich, longitudinal information on financial outcomes for a large panel of U.S. adults over age 50. Linking the HRS to Medicare claims data enabled us to identify individuals who were diagnosed with AD by a physician and their date of diagnosis, so that we could look backward over time at the vulnerable period prior to diagnosis. We found robust evidence that early stage AD heightens the risk of a large adverse change in liquid assets and reduces net wealth. Our evidence showed that these adverse financial outcomes are more likely in AD-afflicted households regardless of who in the household is afflicted—the financial head of household or someone else. We found some, but limited, evidence that the effects on liquid assets and net wealth are greater in magnitude when the financial head of household is afflicted.

## 2. KEYWORDS

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Alzheimer’s Disease, dementia, assets, savings, wealth, debt, financial outcomes

## 3. ACCOMPLISHMENTS

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- **Major Goals**

Our specific aims are to (1) estimate the effects of AD during the period before it is diagnosable on household financial outcomes and (2) determine how the effects of AD during the period before it is diagnosable on financial outcomes differ depending on whether the financial head of household is afflicted or the spouse or partner of the financial head of household is afflicted.

**Major Task 1:** Submit data applications, including IRB application as well as application to

HRS/CMS for restricted use data. *Anticipated Timeframe: Month 1. Completion: 100 percent*

**Major Task 2: Identify individuals with relevant conditions from linked HRS/Medicare claims data and construct observation periods.** *Anticipated Timeframe: Months 1-5. Completion: 100 percent.*

- **Milestone 1:** Apply algorithms to identify individuals with specific health conditions from the Medicare claims data. Identify date of diagnosis for individuals with AD and dementia. *(Completed)*
- **Milestone 2:** Construct the asymptomatic pre-diagnosis period (T1) and the symptomatic pre-diagnosis period (T2) for individuals diagnosed with AD. *(Completed)*

**Major Task 3: Construct variables and perform analyses.** *Anticipated Timeline: Months 5-16 Completion: 100 percent.*

- **Milestone 3:** Construct variables for the empirical models, including indicator for financial head of household. *(Completed)*
- **Milestone 4:** Conduct descriptive analyses. *(Completed)*
- **Milestone 5:** Estimate difference-in-differences models; conduct sensitivity analyses. *(Completed)*

**Major Task 4: Assess potential selection bias using treatment effects model.** *Anticipated timeline: Months 15-20. Completion: 100 percent*

- **Milestone 6:** Apply algorithm to identify individuals with probable dementia. *(Completed)*
- **Milestone 7:** Estimate treatment effects model to ascertain if there is any bias associated with using a sample of persons with diagnosed AD in our main analyses; conduct sensitivity analyses. *(Completed)*

**Major Task 5: Manuscript preparation and dissemination.** *Anticipated timeline: Months 12-24. Completion: 100 percent*

- **Milestone 8:** Prepare manuscripts based on the findings. *(Completed first manuscript; we have a second paper nearly ready for submission)*
- **Milestone 9:** Disseminate our findings including presentation at the DoD PRARP In-Progress Review Meeting. *(Completed: We were not asked to present our findings at the In-Progress Review Meeting).*

- **Accomplishments by Goal**

In Year 1, we completed Major Tasks 1 and 2, worked on Major Task 3, and created descriptive tables for eventual use in our report of findings (Major Task 5). In Year 2, we made significant progress on Major Tasks 3, 4 and 5. In Year 3, we completed Major Tasks 3, 4, and 5. Our article was accepted into the journal *Health Economics* and published October 25, 2019:

*Gresenz CR, Mitchell JM, Marrone J, Federoff H. Effect of early-stage Alzheimer's disease on household financial outcomes. Health Economics. 2019;1–20. <https://doi.org/10.1002/hec.3962>*

We have attached this as an appendix. It provides detailed information on our analytic approach and key findings. We disseminated our research through professional research seminars and substantial media outreach, including a Georgetown University press release and interviews with David Brancaccio of NPR's Marketplace; Deborah Hirsch from *HealthDay*, which feeds news outlets such as US News and World Report; and Rachel Nania of AARP. We further disseminated our work through social media, including Twitter (Georgetown School of Nursing and Health Studies, NHS account) and LinkedIn. We have also drafted a second article based on additional findings.

We had originally intended to write a first paper that used 0/1 flags to indicate the waves prior to diagnosis that an individual was likely to be affected by early stage AD and a second paper that used the probability of dementia (imputed), which would allow us to both flexibly estimate the vulnerable time period of mild/moderate symptoms and to assess selection bias associated with diagnosis by allowing us to examine the effects of early symptoms among people who are never diagnosed with AD. The reviewers for our first paper asked for a sensitivity analysis using something other than the flags based on average time to diagnosis, so we used the probability of dementia among the sample of those diagnosed and provided those results. We felt it was too much to also examine the sensitivity of results to using the sample of people who were diagnosed vs undiagnosed/diagnosed in the first paper, but we provide the results of the sensitivity analysis we conducted for Major Task 4 below. We are still determining whether this sensitivity analysis would be a useful addition to the second paper we have drafted.

Table 1 provides estimates of the effect of cognitive status, measured continuously as the probability of dementia (*PD*) on liquid assets and net wealth. *PD* runs from 0 to 1 and we use two different thresholds for defining likely dementia: 0.5 and 0.65, based on the literature. The Table is similar to that in our *Health Economics* paper that uses probability of dementia instead of the 0/1 flag (Table 2 panel D); with the exception that these results use individuals who have likely dementia, regardless of diagnosis (the main paper uses those with diagnosed dementia) and the observation window closes with the first time *PD* is greater than the likely dementia threshold (either 0.5 or 0.65) as opposed to diagnosis. The two first rows of Table 1 report coefficient estimates from an IHS transformation of the continuous values of liquid assets and net wealth. The next four rows report coefficient estimates from linear regression models of the probability of a large adverse change in net wealth or liquid assets, first using a large change defined by the 75<sup>th</sup> percentile threshold value then using a large change defined using the 90<sup>th</sup> percentile threshold value. The first two columns show results for likely dementia defined using  $PD > 0.5$  and the second two columns for likely dementia defined using  $PD > 0.65$ . Superscript letters (*a*, *b*, *c*) in Table 2 indicate the statistical significance of the difference between the coefficient estimates for non-FHoH and FHoH-afflicted households.

For likely dementia defined used a threshold of 0.5 (first two columns), *PD* decreases liquid assets ( $p < .05$ ) for families regardless of who in the family is afflicted and decreases net wealth ( $p < .01$ ). For net wealth, the effect of *PD* is more pronounced when the FHoH is afflicted ( $p < .01$ ). *PD* also increases the probability of a large adverse change, defined using the 90<sup>th</sup> percentile value, in both liquid assets and net wealth. The effect of *PD* on the probability of a large adverse change in net wealth is more pronounced when the FHoH is afflicted ( $p < .01$ ). The

results are similar when probable dementia is defined using  $PD \geq 0.65$  (second two columns). These results are consistent with those from the diagnosed sample and add an additional robustness check on our main findings.

**Table 1: Sensitivity Analysis Including Individuals with Diagnosed and Undiagnosed AD (Based on Imputed Dementia)**

	50% Threshold		65% Threshold	
	All	FHoH	All	FHoH
Liquid Assets: Continuous	-0.512** (0.217)	-0.522** (0.265)	-0.437** (0.208)	-0.464* (0.252)
Net Wealth: Continuous	-0.699*** (0.250)	-1.046*** <sup>c</sup> (0.309)	-0.743*** (0.242)	-0.967*** <sup>c</sup> (0.290)
Liquid Assets: 75 <sup>th</sup> percentile adverse change	0.062* (0.033)	0.063* (0.038)	0.057* (0.031)	0.058 (0.036)
Net Wealth: 75 <sup>th</sup> percentile adverse change	0.062* (0.033)	0.119*** <sup>c</sup> (0.039)	0.045 (0.031)	0.083*** <sup>c</sup> (0.037)
Liquid Assets: 90 <sup>th</sup> percentile adverse change	0.066*** (0.025)	0.072** (0.030)	0.056** (0.023)	0.062** (0.028)
Net Wealth: 90 <sup>th</sup> percentile adverse change	0.058** (0.024)	0.095*** <sup>c</sup> (0.030)	0.059*** (0.023)	0.089*** <sup>b</sup> (0.028)

Note: Table shows coefficient on Pr(Dementia) from household-level fixed effect regressions including time-varying household characteristics as well as state and year fixed effects. Standard errors in parentheses.

Statistical significance of coefficient: \* 10%; \*\* 5%; \*\*\* 1%

Statistical significance of difference between coefficients from regressions for FHoH (shown) versus non-FHoH (not shown): <sup>a</sup> 10%; <sup>b</sup> 5%; <sup>c</sup> 1%

As we previously described, we may include this sensitivity analysis designed to address possible selection (Major Task 4) in the second paper we have drafted. It will depend on the ultimate length and framing of that paper.

- **Training and professional development opportunities**
  - Nothing to report
- **Dissemination of Results to Communities of Interest**
  - We presented our work at the Georgetown University Population Health and Health Services Research Seminar Series on September 19<sup>th</sup>.
  - We presented our work as part of the RAND Health seminar series on November 6.
  - We prepared and released a Georgetown University press release (<https://gumc.georgetown.edu/news-release/heightened-risk-of-adverse-financial-changes-before-alzheimers-diagnosis/>.)

- We did substantial media outreach including the following:
  - We did an interview with David Brancaccio of NPR's Marketplace: <https://www.marketplace.org/shows/marketplace-morning-report/aging-undiagnosed-dementia-financial-exploitation/>
  - NPR also published an article on the findings: <https://www.marketplace.org/2019/10/25/how-undiagnosed-alzheimers-can-impact-personal-finances/>
  - We did an interview with Deborah Hirsch from *HealthDay*, which feeds news outlets such as US News and World Report: <https://consumer.healthday.com/senior-citizen-information-31/senior-citizen-news-778/for-seniors-financial-woes-can-be-forerunner-to-alzheimer-s-751591.html>
  - We did an interview with Rachel Nania from AARP: <https://www.aarp.org/health/dementia/info-2019/early-stage-alzheimers-financial-loss.html>.
  - Other media outlets picked up on the story including:
    - Webmd: <https://www.webmd.com/alzheimers/news/20191029/for-seniors-financial-woes-can-be-forerunner-to-alzheimers#1>
    - Pscyh central: <https://psychcentral.com/news/2019/10/27/early-stages-of-alzheimers-disease-may-pose-risk-for-financial-problems/151374.html>
    - As well as Health News Digest, International Business Times, Daily Mail:
      - <https://psychcentral.com/news/2019/10/27/early-stages-of-alzheimers-disease-may-pose-risk-for-financial-problems/151374.html>
      - [http://www.healthnewsdigest.com/news/Alzheimer\\_Issues\\_680/Heightened-Risk-of-Adverse-Financial-Changes-Before-Alzheimer-s-Diagnosis.shtml](http://www.healthnewsdigest.com/news/Alzheimer_Issues_680/Heightened-Risk-of-Adverse-Financial-Changes-Before-Alzheimer-s-Diagnosis.shtml)
      - <https://www.ibtimes.sg/financial-losses-mount-individuals-just-before-theyre-diagnosed-alzheimers-study-33492>
      - <https://www.dailymail.co.uk/health/article-7610051/Forgetting-pay-bills-time-warning-sign-Alzheimers.html>
    - And we did an interview with the Georgetown *Hoya*: <https://thehoya.com/early-alzheimers-can-lead-to-overspending-study-shows/>
  - We further disseminated our work through social media, including Twitter (Georgetown School of Nursing and Health Studies, NHS account) and LinkedIn.

#### **Plans for next reporting period**

- This is the final reporting period so we have nothing to officially report, but we note that we will continue to engage in dissemination efforts as interest in this topic appears substantial.

#### **4. IMPACT**

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- **Impact on the Development of the Principal Discipline**

- This work makes an important contribution to cost-of-illness studies. In the context of dementia, cost-of-illness studies have focused on economic costs associated with health care for the condition or home care/caregiving required for individuals afflicted by dementia. This work provides a broader lens through which to think about cost-of-illness and will contribute to a more comprehensive understanding of the true costs of dementia.
  - Second, this work makes an important contribution to how we think about valuing screening tools for conditions, especially those for which treatment options are either non-existent or limited. Sources of value are less obvious compared to conditions for which early treatment improves health outcomes; but, in the case of dementia, the signaling value of diagnosis may be very important for avoiding adverse financial outcomes. This work advances the field by quantifying the potential value of that signal.
  - In addition, this work has led us to think more about the relationship between health and wealth more generally—a long-standing issue of concern for health and labor economists—and what other novel data might be combined to address key questions such as the one this research addresses. This work has also helped catalyze ideas around the potential of new data sources—including Medicare claims data combined with a longitudinal consumer credit data—to further examine the nexus between health and wealth, generally, as well as between Alzheimer’s disease and financial outcomes specifically. Dr. Gresenz (PI) was awarded an R56 grant from NIH to conduct the linkage of these two data sources and evaluate the quality of the data match. Ultimately the goal of this newly funded research is to examine more granular financial outcomes for more refined time periods than are available in the HRS and to explore the potential for using credit data to predict who might be at risk for Alzheimer’s disease and should receive more clinical screening.
- **Impact on Other Disciplines**
    - Nothing to Report
  - **Impact on Technology Transfer**
    - Nothing to report
  - **Impact on Society beyond Science and Technology**
    - The research is important at a societal level for providing increased visibility regarding the true costs of dementia and, at the household-level, for helping families recognize the potential vulnerability of their spouses, parents, and loved ones even when cognitive symptoms may be limited. The media and general population interest in our research are a testament to the importance of these findings.
    - In addition, this research highlights the potential role of financial institutions in protecting vulnerable elderly against poor financial outcomes. More needs to be known about the specific types of decisions and choices that underlie the changes in assets and wealth we observe, but these findings mark the beginning of an important area for regulatory focus.
    - This research was foundational and turned anecdotes about vulnerability of those with early stage AD to poor financial outcomes into systematic, empirically based

evidence. It was the seed from which our new research has grown, which will explore the specific types of financial vulnerabilities that are most likely to affect individuals with dementia before it can be diagnosed with currently available tools. Knowing the granular adverse outcomes to which individuals with AD are most susceptible is crucial for designing and targeting interventions to help prevent them.

- Lastly, there is another dimension of the long-term value of the research that this project has helped to seed, and that is the possibility of developing indicators based on refined financial data (credit data, in particular) for identifying people who should receive additional screening for AD.

## 5. CHANGES/PROBLEMS

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- **Changes in Approach and Reasons for Change**

- We modified some specific analytic aspects of the approach we anticipated and described in the proposal based on our work with and assessment of the actual data once we had it. We expanded our control group to include individuals who were cognitively healthy, regardless of whether they had another (non-cognitive) chronic condition, in order to increase our sample size. We had planned to study foreclosure as an outcome, but the prevalence of foreclosures in the data is very limited and the variation is insufficient for studying foreclosures as a separate outcome. We also tried a summary variable that combined foreclosure with other infrequent but significant outcomes, but variation in this summary outcome was still insufficient for analysis. Additionally, our analyses use ICD9-CM codes that identify Alzheimer's Disease and related dementias (ADR) instead of AD alone as originally planned. We made this change because the ADR group includes households in which an individual has AD but is classified in a more general diagnosis category, such as senile dementia, and to capture individuals who have mixed dementia (AD and some other form). In sensitivity analyses of all individuals with dementia (vs only those with diagnosed dementia), we compared our main results for those with diagnosed dementia to results from a single-stage analysis of all individuals with probable dementia to ensure the conceptual similarity of the windows of observation prior to onset of dementia. In our main analyses, we anticipated that our primary approach would be a difference-in-differences model and estimated this type of model using propensity score matching, but our models using fixed effects were more highly regarded by reviewers and the results largely robust across the two approaches, so our published analyses focuses on the fixed-effects models.

- **Actual or Anticipated Problems or Delays and Actions or Plans to Resolve Them**

- The approval/arrival of our data in Year 1 took longer than we anticipated. While we waited for the data, we made significant progress using the public use HRS data. However, we required a 1-year no cost extension in order to complete our work, including submission of our findings for review and revisions in response to reviewers.

- **Changes That Had a Significant Impact on Expenditures**

- The delay in data slowed down our spending in Year 1. We made steady and consistent progress in Years 2 and 3, and completed spending at the end of Year 3.

- **Significant Changes in Use or Care of Human Subjects, Vertebrate Animals, Biohazards, and/or Select Agents**
  - No significant deviations, unexpected outcomes, or changes in approved protocols for the use or care of human subjects, vertebrate animals, biohazards, and/or select agents during the reporting period.
  - Institutional Review Board approval dates:
    - Human Resources Protection Office (HRPO) Protocol [HRPO Assigned Number]: A-19817; Title: Effects of Alzheimer's Disease in the Pre-diagnosis Period on Financial Outcomes; HRPO contact: Karen Eaton, Human Subjects Protection Scientist
    - Initial IRB review approved by RAND IRB (Human Subjects Protection Committee) for period from 5/31/16-5/30/2017 (HSPC ID 2016-0395). IRB memorandum received June 2, 2016.
    - Continuing review approved by RAND IRB (HSPC) on May 1, 2017, expired 30 May 2018. HRPO continuing review acknowledgement memorandum, received May 31 2017.
    - Continuing review approved by RAND IRB (HSPC) on April 20, 2018, expires 19 April 2019. HRPO continuing review acknowledgement memorandum, received 4 June 2018.
    - Continuing review approved by RAND IRB (HSPC) on 4 March 2019, expires 3 March 2020. HRPO continuing review acknowledgement memorandum, received 23 April 2019.

## 6. PRODUCTS

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- **Publications, conference papers, and presentations**
  - **Journal publications.**
    - Gresenz CR, Mitchell JM, Marrone J, Federoff H. Effect of early stage Alzheimer's disease on household financial outcomes. Health Economics. 2019;1-12. <https://doi.org/10.1002/hec.3962>. Published. Federal support acknowledged.
  - **Books or other non-periodical, one-time publications:** Nothing to report
  - **Other publications, conference papers, and presentations:**
    - We presented our work at the Georgetown University Population Health and Health Services Research Seminar Series on September 19, 2018 and at RAND Health seminar series on November 6, 2018.
- **Website(s) or other Internet site(s):**
  - Georgetown University press release (<https://gumc.georgetown.edu/news-release/heightened-risk-of-adverse-financial-changes-before-alzheimers-diagnosis/>.)
  - Interview with David Brancaccio of NPR's Marketplace: <https://www.marketplace.org/shows/marketplace-morning-report/aging-undiagnosed-dementia-financial-exploitation/>

- NPR article on the findings: <https://www.marketplace.org/2019/10/25/how-undiagnosed-alzheimers-can-impact-personal-finances/>
- Deborah Hirsch from *HealthDay*, article: <https://consumer.healthday.com/senior-citizen-information-31/senior-citizen-news-778/for-seniors-financial-woes-can-be-forerunner-to-alzheimer-s-751591.html>
- AARP article: <https://www.aarp.org/health/dementia/info-2019/early-stage-alzheimers-financial-loss.html>.
- Webmd: <https://www.webmd.com/alzheimers/news/20191029/for-seniors-financial-woes-can-be-forerunner-to-alzheimers#1>
- Psych central: <https://psychcentral.com/news/2019/10/27/early-stages-of-alzheimers-disease-may-pose-risk-for-financial-problems/151374.html>
- Health News Digest: [http://www.healthnewsdigest.com/news/Alzheimer\\_Issues\\_680/Heightened-Risk-of-Adverse-Financial-Changes-Before-Alzheimer-s-Diagnosis.shtml](http://www.healthnewsdigest.com/news/Alzheimer_Issues_680/Heightened-Risk-of-Adverse-Financial-Changes-Before-Alzheimer-s-Diagnosis.shtml)
- International Business Times: <https://www.ibtimes.sg/financial-losses-mount-individuals-just-before-theyre-diagnosed-alzheimers-study-33492>
- Daily Mail: <https://www.dailymail.co.uk/health/article-7610051/Forgetting-pay-bills-time-warning-sign-Alzheimers.html>
- Georgetown *Hoya*: <https://thehoya.com/early-alzheimers-can-lead-to-overspending-study-shows/>
- **Technologies or techniques:** Nothing to report
- **Inventions, patent applications, and/or licenses:** Nothing to report
- **Other Products:** Nothing to report

## 7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

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- **What individuals have worked on the project?**

Name:	Carole Roan Gresenz
Project Role:	PI
Researcher Identifier (e.g. ORCID ID):	0000-0002-7381-7914
Nearest person month worked:	2 (Year 3)
Contribution to Project:	Dr. Gresenz had overarching responsibility for the project. Together with Dr. Mitchell, she oversaw the work of Dr. Marrone. In Year 3, Dr. Gresenz led the work of the team through the process of publication. She took the lead on revising the paper and preparing reviewer responses during the multiple-stage review process. She has also taken the lead on dissemination efforts. She coordinated the work of the team by leading regular team meetings and has taken primary responsibility for all reporting tasks.
Funding Support:	In addition to this award, Dr. Gresenz receives support from AHRQ for a study of how physician practice structure and compensation characteristics affect prostate

	cancer treatment outcomes (PI: Mitchell). In addition, Dr. Gresenz is a co-investigator on an AHRQ funded grant to evaluate a dental care program in Virginia (PI: Mitchell). Dr. Gresenz also has funding from Georgetown University for work to explore racial/ethnic disparities in surgical outcomes. Dr. Gresenz is PI of an R56 grant from NIH to merge credit data with Medicare claims data, in order to further explore questions related to financial outcomes associated with early stage dementia.
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Name:	Jean Mitchell
Project Role:	Co-investigator
Researcher Identifier (e.g. ORCID ID):	0000-0002-2765-4624
Nearest person month worked:	1 (Year 3)
Contribution to Project:	Dr. Mitchell contributed to all aspects of the research project, including design of analyses, interpretation of results, writing and editing draft papers. She participated in regular team meetings.
Funding Support:	In addition to this award, Dr. Mitchell serves as PI for a grant funded by AHRQ to examine the influence of physician practice structure and compensation characteristics affect prostate cancer treatment outcomes among men with low-risk prostate cancer. Dr. Mitchell also serves as PI for a grant funded by the National Cancer Institute to evaluate treatment patterns and health outcomes among women with newly diagnosed ductal carcinoma. Dr. Mitchell is also PI on an AHRQ grant to evaluate an innovative model of dental care. Lastly, Dr. Mitchell is a co-investigator on an NIH R56 grant (PI: Gresenz) to merge credit data with Medicare claims data.

Name:	James Marrone
Project Role:	Co-investigator
Researcher Identifier (e.g. ORCID ID):	0000-0002-8125-6598
Nearest person month worked:	2 (Year 3)
Contribution to Project:	Dr. Marrone implemented the analyses of the merged HRS-Medicare data and contributed to analytic decisions regarding their design and specification. He contributed to the writing and re-writing of the <i>Health Economics</i> publication and implemented all the revised analyses, specification tests and sensitivity analyses in response to reviewers. He has implemented all the analytic work for the second paper.
Funding Support:	Dr. Marrone also serves as principal investigator for a grant from OSD to study attrition among first-term service members across all branches of the military. He has funding from the NBER's DRC to study the impact of interstate migration on

	<p>disability insurance applications. He is also a researcher on projects supported by State Department, conducting international CVE program evaluations; FEMA, analyzing disaster recovery efforts; and U.S. Army, examining the impact of senior enlisted soldiers on junior enlisted attrition.</p>
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- **Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**

- Dr. Gresenz

- The following are changes between our last reporting period (which covered the time period through 9/30/18) and 9/30/19.
    - *Previously active projects now completed*
      - None to report
    - *Pending support now active*
      - None to report
    - *New active support*
      - Dr. Gresenz is PI of a pilot grant from Georgetown University to study racial/ethnic disparities in emergency surgery outcomes (5 percent time).
      - Dr. Gresenz is a co-investigator on an AHRQ-funded project, “Evaluation of an Innovative School-Based Initiative to Improve Receipt of Preventive Dental Care among Children Enrolled in Medicaid.” This project (PI: Dr. Jean Mitchell) began July 2019. Effort: 10 percent.

- Dr. Mitchell

- *Previously active projects now completed*
      - None to report.
    - *Pending support now active*
      - None to report
    - *New active support*
      - Dr. Mitchell is PI for an AHRQ-funded project, “Evaluation of an Innovative School-Based Initiative to Improve Receipt of Preventive Dental Care among Children Enrolled in Medicaid.” This project began July 2019 and supports approximately 20 percent of her time.

- **What other organizations were involved as partners?**

We partnered with Georgetown University and the University of California-Irvine (UCI). One of the project’s co-investigators (Dr. Mitchell) is affiliated with GU and our research assistant is also at GU. (Dr. Gresenz also now has an appointment at GU but her work on this project began when she was at RAND and continued there until completion.) We also have collaborated with Dr. Howard Federoff of UC Irvine.

- Organization Name: Georgetown University (academic institution)

- Location of Organization: Washington, DC
- Partner's contribution to the project
  - *Facilities*
    - Dr. Mitchell's affiliation is with Georgetown University. She uses GU facilities to conduct her work, including her office and computing equipment. The research assistant, Caitlin Chamberlain, also is associated with GU and conducts her work using computing technology from the University.
  - *Collaboration*
    - Dr. Mitchell is a co-investigator on the award. She collaborates with Dr. Gresenz on all aspects of the project and additionally oversees a research assistant, also from GU, who also contributes to the project.
    - Dr. Gresenz also now has an appointment at GU.
- Organization Name: University of California-Irvine (academic institution)
- Location of Organization: Irvine, CA
- Partner's contribution to the project
  - *Facilities*
    - Dr. Federoff's affiliation is UCI. He uses UCI facilities to conduct his work, including his office and computing equipment.
  - *Collaboration*
    - Dr. Federoff has provided expert consultation on clinical aspects of dementia and AD that affect our work. He provided us with information about appropriate use of diagnostic codes related to AD/dementia and helped us with clinical knowledge related to the timing of the typical progression of disease from cognitive normalcy through MCI to severe dementia.

## 8. SPECIAL REPORTING REQUIREMENTS

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- **QUAD CHART**
  - Attached.

## 9. APPENDICES

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- (A) *Health Economics* publication
- (B) Georgetown University Medical Center (GUMC) press release
- (C) Bibliography, meeting abstracts, list of personnel

# Effects of Alzheimer's Disease in the Prediagnosis Period on Financial Outcomes

AZ150099

W81XWH-16-1-0746

PI: Carole Roan Gresenz

Org: RAND Corporation

Award Amount: \$757,578



- Study/Product Aims**
- Estimate the effects of AD during the period before it is diagnosable on household financial outcomes.

- Determine how the effects of AD during the period before it is diagnosable on financial outcomes differ depending on whether the financial head of household is afflicted or the spouse or partner of the financial head of household is afflicted.

## Approach

We analyze Health and Retirement Study (HRS) data linked to Medicare claims data. The HRS includes rich, longitudinal information on financial outcomes for a large panel of U.S. adults over age 50. Linking the HRS to Medicare claims data enables us to identify individuals who were diagnosed with AD by a physician and their date of diagnosis, so that we can look backward over time at the vulnerable period *prior* to diagnosis. We use a difference-in-differences approach to evaluate the effect of AD during the period before the disease is diagnosable on financial outcomes.

## Timeline and Cost

Activities	Q1-Q2	Q3-Q4	Q5-Q6	Q7-12
Apply for and obtain restricted use data (IRB, HRS, CMS applications)	█	█		
Identify analytic sample using merged data; construct observation periods		█	█	
Construct variables and perform analyses	█	█	█	█
Manuscript prep and dissemination			█	█
<b>Estimated Budget (\$K)</b>	<b>\$381,662</b>		<b>\$375,916</b>	

Updated: 30 Sep 2019



Accomplishments (Q12): Paper accepted at Health Economics; drafted press release; completed draft of second paper that looks at outcomes for all individuals with dementia regardless of diagnosis.

**Goals/Milestones** █ Not begun █ Begun, not complete █ Complete  
**Year 1 Goals/Milestones**

- Milestone 1/2:** Identify treatment and controls from merged data and construct observation periods
- Milestone 3/4:** Construct variables and conduct descriptive analyses.

**Goals/Milestones Spanning Years 1-2**

- Milestone 5:** Estimate difference-in-differences models; conduct sensitivity analyses.

**Year 2 Goals/Milestones**

- Milestone 6/7:** Apply algorithm to identify individuals with probable dementia and test sensitivity to selection on AD diagnosis
  - Milestone 8/9:** Prepare manuscripts and disseminate results
- Comments/Challenges/Issues/Concerns**

- None

**Budget Expenditure to Date**

Projected Expenditure: Straight line expenditures over project life

Actual Expenditure: **\$757,578**

# Effect of early-stage Alzheimer's disease on household financial outcomes

Carole Roan Gresenz<sup>1</sup>  | Jean M. Mitchell<sup>2</sup>  | James Marrone<sup>3</sup> |  
Howard J. Federoff<sup>4</sup> 

<sup>1</sup>Department of Health Systems Administration, Georgetown University, Washington, D.C., USA

<sup>2</sup>McCourt School of Public Policy, Georgetown University, Washington, D.C., USA

<sup>3</sup>RAND Corporation, Arlington, Virginia

<sup>4</sup>Department of Neurology, School of Medicine, Henry and Susan Samueli College of Health Sciences, University of California-Irvine, Irvine, California

## Correspondence

Carole Roan Gresenz, Department of Health Systems Administration, St. Mary's Hall, Georgetown University, 3700 Reservoir Road NW, Washington DC 20007.

Email: carole.roan.gresenz@georgetown.edu

## Funding information

Office of the Assistant Secretary of Defense for Health Affairs; DoD Alzheimer's Research Program Quality of Life Research Award, Grant/Award Number: W81XWH-16-1-0746

## Abstract

Significant limitations and rapid declines in financial capacity are a hallmark of patients with early-stage Alzheimer's disease (AD). We use linked Health and Retirement Study and Medicare claims data spanning 1992–2014 to examine the effect of early-stage AD, from the start of first symptoms to diagnosis, on household financial outcomes. We estimate household fixed-effects models and examine continuous measures of liquid assets and net wealth, as well as dichotomous indicators for a large change in either outcome. We find robust evidence that early-stage AD places households at significant risk for large adverse changes in liquid assets. Further, we find some, but more limited, evidence that early-stage AD reduces net wealth. Our findings are consequential because financial vulnerability during the disease's early-stage impacts the ability of afflicted individuals and their families to pay for care in the disease's later stage. Additionally, the findings speak to the value that earlier diagnosis may provide by helping avert adverse financial outcomes that occur before the disease is currently diagnosable with available tools. These results also point to a potentially important role for financial institutions in helping reduce exposure of vulnerable elderly to poor outcomes.

## KEYWORDS

consumer protection, health, household behavior and family economics, household saving, personal finance

## 1 | INTRODUCTION

Dementia due to Alzheimer's disease (AD) affects an estimated 5.5 million individuals in the United States and ~50 million worldwide, exacting substantial and increasing human and monetary costs (Alzheimer's Association, 2019; Hurd, Martorell, Delavande, Mullen, & Langa, 2013a, 2013b). Individuals with AD typically experience a multiyear period in which they are mildly to moderately symptomatic, with the disease first affecting complex activities of daily living (such as taking daily medications, driving, and financial management), followed by basic activities of daily living (such as toileting, dressing, bathing, and grooming; Department of Health and Human Services, 2016). Diagnosis of AD currently occurs in the disease's later stage, after the onset of severe symptoms and impairment, given available diagnostic tools (Alzheimer's Association, 2019; Brookmeyer, Corrada, Curriero, & Kawas, 2002). The time period when individuals are experiencing mild to moderate cognitive impairment but before the disease is diagnosable represents a uniquely vulnerable period for individuals and households, especially with regard to financial outcomes (Wood & Lichtenberg, 2017).

The financial vulnerability of individuals with early-stage AD reflects several factors. First, significant limitations and rapid declines in financial capacity have been increasingly recognized as hallmarks of patients with early-stage AD (Marson et al., 2000; Martin et al., 2008; Triebel et al., 2009). Marson et al. (2000) defines financial capacity as the ability to manage money and financial assets in ways consistent with an individual's values and/or self-interest. Testing a set of 14 financial tasks including checkbook and bank statement management, financial judgment, and basic monetary skills such as counting change, Marson et al. (2000) find that patients with mild cognitive impairment are relatively impaired at performing more complex financial tasks (such as using a checkbook/register and making investment decisions) and those with moderate cognitive impairment are relatively impaired in conducting both simple and complex financial tasks. Martin et al. (2008) and Triebel et al. (2009) find substantial declines in financial capacity over the course of 1 year among individuals with mild cognitive impairment.

Such studies of the effect of cognitive impairments associated with AD on financial capacity complement and extend other research that has found a relationship between cognitive ability, more generally, and financial decision making. Previous research finds that cognitive skills are related to wealth and wealth composition (McArdle, Smith, & Willis, 2011) and that cognitive ability affects the type of investments that individuals make (with higher cognitive ability associated with a greater share of assets in stocks) and investment returns (Agarwal & Mazumder, 2013; Grinblatt, Keloharju, & Linnainmaa, 2012). A recent study by Shin, Lillard, and Bhattacharya (2019) sits at the intersection of these two literatures, examining how the genetic risk of developing AD relates to the type of assets in which individuals hold their savings. The authors find that as people genetically predisposed to AD age, they save more in assets that require less active management.

Declining financial skills associated with early-stage AD may affect an individual's ability to sustain processes and behaviors that have guided their financial lives prior to cognitive impairment, such as those that ensure bills are paid on time, spending is kept in check, and investments are wise. At the same time that individuals with early-stage AD may by themselves be susceptible to poor financial outcomes, they are also more likely to be susceptible to financial exploitation and fraud by others (Stiegel, 2012; Wood & Lichtenberg, 2017). The National Center on Elder Abuse defines financial exploitation as the misappropriation of an older person's money or property (National Center on Elder Abuse, 2019), which can take forms such as theft, scams, unauthorized access to accounts, and improper use of guardianship (Wood & Lichtenberg, 2017). Previous research has found that elder financial exploitation and fraud is common. Burnes et al. (August 1, 2017) estimate that financial fraud affects one out of every 18 cognitively intact, community dwelling older adults each year, and DeLiema, Deevy, Lusardi, and Mitchell (2019) find that 5% of adults aged 50 and over experienced at least one form of investment fraud and 4.4% were subjected to prize or lottery fraud. The Consumer Financial Protection Bureau documents a quadrupling in suspicious activity reports filed on elder financial exploitation between 2013 and 2017 (Consumer Financial Protection Bureau, 2019).

Judges, Gallant, Yang, and Lee (2017), studying a nondemented sample of older adults, find that fraud victims have relatively low levels of cognitive ability. The Consumer Fraud Research Group (2006) finds that low levels of financial literacy are associated with susceptibility to lottery scams, whereas high levels of financial literacy are associated with investment fraud, with scammers targeting individuals with a particular scam depending on their traits and psychological profile. DeLiema et al. (2019) find no relationship between financial literacy and cognitive status and exposure to fraud, using a small subsample of Health and Retirement Study (HRS) respondents. Though the empirical evidence to date is mixed, Wood and Lichtenberg reflect that individuals who are mildly impaired prior to AD are, conceptually, the "perfect victim," as they have control of their assets but have impairments that may not be recognized and have broad exposure to the community.

Thus, both as a consequence of individuals' susceptibility to making poor financial decisions on their own, as well their vulnerability to the malfeasance of others, individuals with AD and their families are at significant risk for negative economic consequences during the symptomatic period prior to diagnosis. In the early stage of the disease prior to diagnosis, an individual's financial decision-making limitations may not be fully appreciated or recognized (Okonkwo et al., 2008), and diagnosis can serve as a trigger for the institution of checks and balances on an individual's financial decision making (Hsu & Willis, 2013). The average length of time that it takes an individual to progress through the early stage of AD, from the first symptoms of impairment to a diagnosis of dementia, is 2.8 years, according to findings from the Baltimore Longitudinal Study of Aging (Brookmeyer et al., 2002). Thus, individuals and their families are often at risk from the consequences of financial decision-making deficits associated with early-stage AD for a multiyear period.

To our knowledge, no studies have examined the financial consequences of early-stage AD. Our goal in this study is estimate, on net, the financial effects of early-stage AD, from the start of first symptoms to diagnosis, on individuals and their families. Additionally, we examine whether the effects of early-stage AD vary depending on who within the

household is affected. Because two-adult households often vest authority over financial decisions with one individual who has comparative advantage in that domain (Becker 1993; Hsu & Willis, 2013), the susceptibility of households to adverse financial outcomes is likely to be heightened when the financial head of household (FHoH) is afflicted with early-stage AD. This is similarly the case for individuals living alone. In two adult households, when spouses or partners of financial heads are afflicted, the effect of the early stage of the disease financial outcomes may be somewhat ameliorated but still consequential as the non-FHoH may retain immediate discretion over spending through access to credit cards, checkbooks, and cash.

## 2 | METHODS

### 2.1 | Health and Retirement Study

We rely on data from the HRS, a nationally representative, longitudinal study of Americans over the age of 50 sponsored by the National Institute on Aging linked to Medicare fee-for-service claims data. HRS respondents are interviewed every 2 years about their health, work and retirement, finances, and family characteristics. The first HRS data were collected in 1992, and new cohorts have been added over time every several years to maintain a steady-state representation of the U.S. population over the age 50. The length of the panel varies for respondents depending on their cohort: Respondents in the earliest cohort (1992) have data potentially spanning 20+ years; those in the more recent cohorts have shorter panels. The first cohort (1992) is the HRS (Health and Retirement); the AHEAD (Aging and Health Dynamics) cohort began in 1993; the War Baby (WB) and Children of Depression (CODA) cohorts began in 1998; the Early Boomer (EBB) cohort started in 2004, the Mid Boomers (MBB) in 2010, and the Late Boomers (LB) in 2016. Since 1998, each wave has included roughly 20,000 interviews.

The HRS samples households with at least one age-eligible person and collects information for the household financial unit, which includes the age-eligible person and his/her spouse or partner. Thus, household financial units (which we will call “households”) include either one or two HRS respondents.<sup>1</sup> Although non-age eligible spouses/partners are also HRS respondents, our analytic sample includes HRS households for which linked claims data are available for both respondents in two-respondent households or for the single respondent in one-respondent households. For each household in the HRS, we create an eligibility window that includes the set of waves during which household structure is stable with regard to marital status and number of respondents in the household.

Each wave of the HRS includes a battery of questions about households' financial assets and liabilities. Financial outcomes are self-reported, but the HRS has developed methods to ameliorate nonresponse and improve the accuracy of such data, including the use of unfolding brackets and improvements in question ordering (Hauser & Willis, 2004). In addition, the HRS instituted an “asset reconciliation” component to the HRS study design (Moldoff et al., 2013). The section is meant to verify large discrepancies in asset values between waves, ensuring the change is real and not a reporting or data entry error.<sup>2</sup>

### 2.2 | Linked data

We link panel data from the HRS spanning 1992–2014 with multiple other sources of data. First, we link the HRS to Medicare claims data, available from 1992 forward, using processes established by HRS and the Center for Medicare/Medicaid Services (CMS; HRS, 2016). We use linked HRS/Medicare data in order to identify individuals who have been diagnosed with AD and the timing of the date of diagnosis with better accuracy compared with self-reported diagnosis of dementia (which is available in the unlinked HRS). Previous research has employed a claims-based approach to identifying AD and to establishing date of diagnosis (Joyce et al., 2007; Taylor, Fillenbaum, & Ezell, 2002). We note that although the Aging, Demographics, and Memory Study (ADAMS) module of the HRS contains information on AD and dementia from a clinical evaluation (HRS, 2013), this is only available for a small subset of all HRS respondents,

<sup>1</sup>If a sampled household has more than one unrelated age-eligible person, only one person from the household is selected for the HRS.

<sup>2</sup>The HRS also includes questions about experiences of financial distress, such as falling behind on a mortgage or experiencing a foreclosure. However, these variables are only available in a limited number of waves (2008 forward) and the majority of respondents in our analytic sample did not report having a mortgage.

and the sample size is not sufficient for analyzing financial outcomes. Finally, although the HRS assesses cognitive symptoms for respondents in most waves, we require information on whether and when AD was diagnosed.

We employ a well-established algorithm developed by CMS for identifying AD using claims data, which requires the presence of certain ICD9-CM codes during a 3-year reference period. Beneficiaries must have at least one inpatient, skilled nursing facility, home health, Part B institutional, or Part B non-institutional (carrier) claim with specified diagnosis code in any position during the period (CMS, 2017). The algorithm identifies AD using the ICD9-CM code 331.0 and AD and related dementias using the following set of ICD9-CM codes: 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.10, 294.11, 294.8, 797 (CMS, 2017). Taylor, Østbye, Langa, Weir, and Plassman (2009) estimate the sensitivity and specificity of claims data for identifying AD to be .64 and .95, respectively (with some of the individuals coded as false positives for AD having another form of dementia as opposed to not being demented; Taylor et al., 2009). Claims data offer better sensitivity (.85) for identifying the broader class of AD and related dementias (ADRD; Taylor et al., 2009). Although the latter (ADRD) offers better sensitivity compared to AD alone, we recognize that cognitive profiles of dementia vary by subtype. Some forms of dementia, such as dementia with Lewy bodies, share common memory symptoms with AD and have been shown to be associated with deficits in financial decision making (Martin et al., 2013). Frontotemporal lobe dementia is not typically characterized by the same degree of memory loss in the early stage as with AD, and memory symptoms associated with vascular dementia depend on the location and severity of blood vessel damage (Alzheimer's Association, 2019). However, it is increasingly recognized that various forms of dementia commonly co-occur, such as vascular dementia or frontotemporal lobe dementia mixed with AD. Additionally, individuals with AD may be classified in some of the more general diagnosis codes included in ADRD, such as senile dementia. Our analyses use ADRD as this group of individuals includes households in which an individual has mixed dementia (AD and some other form) and households in which an individual has AD but is classified in another diagnostic category. We identify the date of diagnosis using the first date that the relevant diagnosis code is observed in the claims data.

We merge variables to the HRS that capture imputed probable cognitive status for each respondent in each wave (Hurd et al., 2013a). These are based on a statistical prediction model of cognitive status developed using a subsample of HRS respondents who participated ADAMS (HRS, 2013)—which identifies respondents who have dementia based on in-home, clinical cognitive assessments. Hurd et al. (2013a) apply the predictive model to all HRS respondents age 65 and over for all but the first three waves of the HRS (because of differences in data availability in these waves). We use the imputed probability of dementia in sensitivity analyses as an alternative way to identify the waves in which individuals are likely experiencing mild to moderate cognitive impairment prior to diagnosis. We also use this information along with other information from the HRS survey and from claims data to define a cognitively healthy comparison group. Comparison group households are those in which individuals in the household have no diagnosed dementia based on claims data, are not imputed to have probable dementia, and do not self-report ever having been diagnosed with dementia or a memory disorder.

### 2.3 | Empirical strategy

We estimate household fixed-effects models in which each household acts as its own control and identification comes from within household changes over time. Our main analytic sample includes households in which an individual is afflicted by ADRD as well as cognitively healthy households not afflicted by the disease; the latter are included to contribute to the identification of parameters other than the effect of the disease's early stage. Our main model follows Equation (1) below.

$$F_{ht} = \beta_0 + \beta_1 \mathbf{X}_{ht} + \beta_2 ES_{ht} + \lambda_h + \delta_t + \xi_s + \varepsilon_{ht}, \quad (1)$$

where  $F$  is a financial outcome for household  $h$  in time  $t$ ;  $\mathbf{X}$  includes time-varying sociodemographic and health status characteristics of the household;  $ES$  (early stage) is a dichotomous indicator that is set equal to 1 if an individual in the household is experiencing early-stage AD (see below) in time period  $t$ ; and  $\lambda_h$  are household fixed effects,  $\delta_t$  are time fixed effects, and  $\xi_s$  are state fixed effects.

Our vector of household characteristics ( $\mathbf{X}$ ) includes age (of the oldest respondent, specified with dummy variables for seven age groups), number of residents in the household, labor force participation (dichotomous indicator for participation by any household member), income, functional limitations (index value for the more limited respondent), a set of indicators for each of seven chronic conditions, dual Medicaid/Medicare enrollment (either respondent), and household

out-of-pocket medical expenditures.<sup>3</sup> We interact an indicator for whether a household is ever afflicted by ADRD with the age group and chronic condition variables to allow their effects to vary across ADRD and comparison group households.<sup>4</sup> Households not afflicted by AD have  $ES = 0$  for all time periods, and these households contribute to the identification of parameters other than  $\beta_2$ ; only households who are afflicted by ADRD contribute to the identification of  $\beta_2$ , which is the key parameter of interest.

For households afflicted by ADRD, the  $ES$  indicator is set equal to 1 for the two HRS interviews prior to diagnosis and is set equal to 0 for earlier interviews. Thus, for example, for an individual diagnosed in 2012 or 2013, the flag is turned on for the 2012 and the 2010 interviews and captures the time period spanning approximately 2–3 years prior to diagnosis (depending on the exact timing of the interview and diagnosis). The coefficient on this indicator variable reflects the effect of early-stage AD on financial outcomes for an average window over which individuals experience cognitive symptoms prior to diagnosis, as best approximated by our data and based on the typical length of progression from first symptoms of cognitive impairment to diagnosis (Alzheimer's Association, 2019; Brookmeyer et al., 2002; Petersen et al., 1999).<sup>5</sup> To ameliorate the possibility that we capture some postdiagnosis financial outcomes for individuals diagnosed in an interview year (i.e., some individuals diagnosed in 2012 may have responded to their HRS interview after their diagnosis in that year), we conduct sensitivity analyses in which we exclude information from the wave of diagnosis.

Our financial outcomes  $F_h$  include a measure of *liquid assets*, including money in checking, savings, and money market accounts, and *total nonhousing wealth*, defined as nonhousing assets—including money in checking/savings/money market accounts, bonds, stocks, other assets—less nonhousing debt—including credit card debt, medical debt, life insurance policy loans, loans from relatives, and other debt. Net wealth includes negative and positive values, liquid assets have a mass at zero (see Table 2), and both outcomes are skewed. We follow the literature by transforming these outcomes using an inverse hyperbolic sine (IHS) transformation (see, e.g., Burbidge, Magee, & Robb, 1988; Pence, 2006), which approximates the log transformation but allows for nonpositive values and dampens extreme values (outliers), which is useful for ameliorating heteroscedasticity. We also analyze dichotomous indicators for a large adverse change in liquid assets or net wealth (decrease in assets, decrease in net wealth). We define a “large” adverse change as one that in percentage terms is greater than the 75th percentile or 90th percentile of all observed adverse changes for the analytic sample. We analyze these outcomes using fixed-effect linear probability models (Konetzka, Stuart, & Werner, 2018; Marton, Yelowitz, & Talbert, 2014). We chose this estimation approach over alternatives (fixed effect logit or conditional logit models) to avoid issues associated with the incidental parameter problem and facilitate estimation of marginal effects (Angrist & Pischke, 2009; Greene, 2004; Neyman & Scott, 1948). We cluster the standard errors at the household level in all analyses.

We first perform our analyses using households in which any respondent is diagnosed with AD and then use the subset of households in which the FHoH is afflicted to examine whether effects on financial outcomes vary depending on who within the household has the disease. (In the latter models, households in which the non-FHoH is afflicted are dropped from analyses.)

## 2.4 | Sensitivity analyses

We conduct several sensitivity analyses to test the robustness of our findings. First, we exclude information from the wave of diagnosis (for afflicted households) to address the possibility that we capture some postdiagnosis financial outcomes for individuals diagnosed in an interview year. Second, we exclude any households in which an individual is dually eligible for Medicaid and Medicare. Third, we conduct additional analyses in which we replace the flags for early-stage AD-affected waves (based on the average time from mild symptoms to diagnosis) with a variable indicating the imputed probability of dementia in each wave (Hurd et al., 2013a). This variable allows us to flexibly estimate the

<sup>3</sup>The functional limitation index ranges from 0 to 5 and represents the sum of the number of activities of daily living (walking across the room, dressing, showering/bathing, eating, and getting in/out of bed) for which the respondent indicates having any difficulty (Konetzka & Luo, 2011; Salm, 2009). We calculate the index for each respondent, and our measure includes the index value for the most impaired respondent in two-respondent households.

<sup>4</sup>We performed  $t$  tests of the difference between regression coefficients from an analysis using our full sample (ADRD and comparison group households) to an analysis using only ADRD-afflicted households and found no statistically significant differences between coefficients on other variables.

<sup>5</sup>A different approach would be to use claims-based diagnoses of MCI prior to a dementia diagnosis to identify the symptomatic prediagnosis time period, but clinician experts with whom we consulted suggested that physicians did not consistently code MCI in patient records during the time frame of our data.

effect of cognitive impairment during the time period prior to diagnosis. In this analysis, we drop some of the treatment group households (and incur a loss of power), because imputed cognitive status variables are not available for the first three waves of the HRS due to data limitations. Lastly, we conduct our analyses on the subsample of individuals in households who ever experience ADRD, dropping comparison group households.

### 3 | RESULTS

The overall analytic sample includes 8,871 households, including 2,777 households in which someone is diagnosed with ADRD. Of these, the FHoH is afflicted in 2,074 of the ADRD households. For analyses limited to those in which the FHoH is afflicted, we exclude 703 households in which the non-FHoH is afflicted and our analytic sample is 8,168. Table 1 provides descriptive statistics.

Among ADRD households, the FHoH is afflicted in 73% and the non-FHoH is afflicted in 27%. Roughly half of households are two-respondent households (48.4%). The mean number of chronic conditions is 1.9 (normalized for household

**TABLE 1** Descriptive statistics

<b>Households (n)</b>	<b>8,871</b>	<b>2,777</b>	<b>6,094</b>
	Full-sample mean	ADRD-only mean	Non-ADRD mean
FHoH is afflicted by ADRD (%)	23.4	73.2	0
Two respondent household (%)	48.4	47.2	49.0
Married (%)	50.6	48.9	51.8
Divorced/Separated (%)	6.3	2.8	7.8
Widowed (%)	38.0	45.1	34.8
Never married (%)	5.1	4.1	5.6
Less than HS (%)	29.8	36.3	26.8
High school/GED (%)	32.8	31.8	33.3
College or more (%)	37.4	31.9	39.9
Non-White (%)	21.3	23.1	20.4
Foreign-born (%)	10.4	10.8	10.1
<b>Household-waves (n)</b>	<b>32,846</b>	<b>10,552</b>	<b>22,294</b>
	Full-sample mean (SE)	ADRD-only mean (SE)	Non-ADRD mean (SE)
Number of household members	1.96 (1.04)	1.91 (1.08)	1.99 (1.02)
Age (of oldest respondent)	76.1 (6.9)	79.1 (7.1)	74.7 (6.3)
Count of chronic conditions (normalized)	1.95 (1.19)	1.94 (1.24)	1.96 (1.16)
Household respondent in labor force (%)	25.7	16.5	30.1
Household income (\$)	53,417 (80,040)	43,550 (65,099)	58,087 (85,820)
Index of functional status	0.45 (0.99)	0.65 (1.19)	0.36 (0.87)
Dual eligibility (Medicaid/Medicare) (%)	9.0	13.0	7.1
Out of pocket medical expenses (\$)	4,238 (15,020)	4,366 (13,820)	4,177 (15,558)
Liquid assets (\$)	31,786 (63,608)	29,168 (62,998)	33,024 (63,858)
HH with no liquid assets (%)	15.2	19.3	13.2
Mean of liquid assets, among HH with any assets (\$)	37,475 (67,505)	36,154 (68,314)	38,057 (67,140)
One-wave change in liquid assets (\$)	1,415 (64,025)	1,227 (66,924)	1,505 (67,140)
Net wealth (\$)	295,965 (557,431)	243,731 (525,560)	320,687 (570,243)
HH with no or negative net wealth (%)	9.8	12.9	8.3
Net wealth, among HH with negative net wealth (\$)	-8,224 (9,697)	-7,166 (9,370)	-8,685 (9,805)
Net wealth, among HH with positive net wealth (\$)	328,383 (577,579)	280,028 (553,832)	350,132 (586,662)
One-wave change in net wealth (\$)	6,530 (366,443)	8,192 (382,327)	5,734 (358,389)
Large adverse change, liquid assets (%) (75th percentile)	25.0	26.6	24.2
Large adverse change, liquid assets (%) (90th percentile)	10.0	11.8	9.1
Large adverse change, net wealth (%) (75th percentile)	25.0	28.6	23.2
Large adverse change, net wealth (%) (90th percentile)	10.0	13.5	8.3

*Note.* Education is for the respondent with the highest education level. Count of chronic conditions is normalized for household size. Functional status index ranges from 0 to 5 based on any difficulty performing one or more of 5 activities of daily living, with higher numbers indicating more difficulty. The household measure is the greater of the two indices for two-respondent households. Dual eligibility is a 0/1 flag indicating that an individual in the household is enrolled in both Medicaid and Medicare.

Abbreviations: HH, household; FHoH, financial head of household.

**TABLE 2** Effect of early-stage AD on financial outcomes

	Liquid assets		Net wealth	
AD-afflicted household member:	Any	FHoH	Any	FHoH
Panel A: Main results				
Continuous value	−0.094 (0.114)	−0.147 (0.132)	−0.178 (0.128)	−0.164 (0.154)
	<i>32,480</i>	<i>29,816</i>	<i>32,480</i>	<i>29,816</i>
Large adverse change (75th percentile)	0.051** (0.021)	0.067*** (0.024)	0.032 (0.021)	0.039 (0.024)
Large adverse change (90th percentile)	0.033** (0.015)	0.043** (0.018)	0.027* (0.015)	0.023 (0.019)
	<i>23,966</i>	<i>21,956</i>	<i>23,966</i>	<i>21,956</i>
Panel B: Exclude wave of diagnosis				
Continuous value	−0.099 (0.119)	−0.144 (0.138)	−0.188 (0.129)	−0.187 (0.156)
	<i>30,207</i>	<i>28,099</i>	<i>30,207</i>	<i>28,099</i>
Large adverse change (75th percentile)	0.047** (0.022)	0.068*** <sup>a</sup> (0.026)	0.044* (0.023)	0.051* (0.027)
Large adverse change (90th percentile)	0.028* (0.016)	0.041** <sup>a</sup> (0.020)	0.030* (0.017)	0.027 (0.020)
	<i>22,121</i>	<i>20,552</i>	<i>22,121</i>	<i>20,552</i>
Panel C: Exclude dual Medicaid/Medicare				
Continuous value	−0.067 (0.130)	−0.122 (0.157)	−0.103 (0.123)	−0.108 (0.152)
	<i>25,766</i>	<i>23,619</i>	<i>25,766</i>	<i>23,619</i>
Large adverse change (75th percentile)	0.055** (0.024)	0.070** (0.028)	0.036 (0.024)	0.054* (0.028)
Large adverse change (90th percentile)	0.024 (0.017)	0.030 (0.021)	0.027 (0.017)	0.025 (0.022)
	<i>19,089</i>	<i>17,483</i>	<i>19,089</i>	<i>17,483</i>
Panel D: Probability of dementia				
Continuous value	−0.406* (0.221)	−0.414 (0.259)	−0.651** (0.272)	−0.950*** <sup>b</sup> (0.319)
	<i>27,384</i>	<i>24,734</i>	<i>27,384</i>	<i>24,734</i>
Large adverse change (75th percentile)	0.030 (0.031)	0.045 (0.036)	0.081** (0.032)	0.115*** <sup>b</sup> (0.037)
Large adverse change (90th percentile)	0.046* (0.023)	0.043 (0.027)	0.080*** (0.024)	0.110*** <sup>c</sup> (0.029)
	<i>24,015</i>	<i>21,920</i>	<i>24,015</i>	<i>21,920</i>

Note. Standard errors are in parentheses. Superscript letters indicate statistical significance of difference between FHoH coefficient and non-FHoH coefficient: a = 10%, b = 5%, c = 1%. First row in each panel reports coefficient estimates from IHS transformed values of liquid assets and net wealth. Second and third rows report coefficient estimates from linear regressions models. Sample sizes are in italics. In Panel D, the probability of dementia for households without an ADRD diagnosis is the larger of the two respondents' probabilities in analyses in the "Any" column and is the FHoH probability for analyses in the "FHoH" column.

\*Statistical significance at 10%.

\*\*Statistical significance at 5%.

\*\*\*Statistical significance at 1%.

size), and mean functional status is 0.45, where the index runs from 0 to 5 and captures the number of activities of daily living for which an individual reports difficulty. The average levels of liquid assets and net wealth are \$31,786 and \$295,965, respectively. Households have no liquid assets in 15.2% of household-wave observations and zero or negative net wealth in 9.8% of household-wave observations. The 75th percentile value for determining a large reduction in liquid assets is a 60.0% decline (94.5% decline for the 90th percentile threshold) and for net wealth is a 43.1% decline (82.6% decline for the 90th percentile threshold).

Table 2 provides estimates of the effect of early-stage AD on liquid assets and net wealth. Panel A shows the results of our main analyses, and the sensitivity analyses are displayed in Panels B–D. The first row of each panel reports coefficient estimates from an inverse hyperbolic sine transformation of the continuous values of liquid assets and net wealth. The next two rows report coefficient estimates from linear regression models of the probability of a large adverse change in net wealth or liquid assets. The second row shows results for a large change defined using the 75th percentile threshold value and the third row for a large change defined using the 90th percentile threshold value. Superscript letters (*a*, *b*, *c*) in Table 2 indicate the statistical significance of the difference between the coefficient estimates for non-FHoH and FHoH-afflicted households.

The first two columns show results for the financial outcome of liquid assets. In our main analyses, the effect of early-stage AD on the value of liquid assets is not statistically significant when either household member or the FHoH is afflicted. However, early-stage AD increases the probability of a large adverse change in liquid assets for all AD households—regardless of who is afflicted—as well as households in which the FHoH is afflicted. Early-stage AD increases the probability of a large decline in liquid assets, defined using the 75th/90th percentile threshold, by 5.1 and 3.3 percentage points, respectively ( $p < .05$ ). Evaluated at the mean percentage of households with ADRD who experience such

change (Table 1), this represents a 19% increase in the probability of a large adverse change in liquid assets using the 75th percentile threshold and a 27% increase using the 90th percentile threshold. For households in which the FHoH is afflicted, the disease increases the probability of a large (90th percentile-defined) decline in liquid assets by 4.3 percentage points ( $p < .05$ ). The third and fourth columns summarize results for net wealth. We find a weakly statistically significant effect of early-stage AD on a large adverse change (90th percentile) in net wealth ( $p < .10$ ); we otherwise find no statistically significant effects of early-stage AD on net wealth.

We provide results from sensitivity analyses in Panels B and C. In Panel B, to ameliorate the possibility that we capture some postdiagnosis financial outcomes for individuals diagnosed in an interview year, we report the results of sensitivity analyses in which we examine only outcomes in the interview that occurs at least 2 years prior to diagnosis (e.g., 2010 for those diagnosed in 2012), again sacrificing some statistical power. The estimate of the effect of early-stage AD on liquid assets is in the same direction in Panel B, and as in our main analyses, the effect is not statistically significant for either households in which any member is afflicted or the FHoH is afflicted. Consistent with our main analyses, we find early-stage AD increases the probability of a large reduction in liquid assets ( $p < .01$  for FHoH-afflicted households and 75th percentile). The effect is more pronounced for households in which the FHoH is afflicted ( $p < .10$ ). For net wealth, our estimates in Panel B are weakly statistically significant for large adverse changes in net wealth ( $p < .10$  for 90th or 75th percentile change when either household member is affected and for 75th percentile change for FHoH is afflicted). In Panel C, we exclude households that are dual eligible (instead of controlling for dual eligibility in our analyses). For liquid assets, we again find that early-stage AD increases the probability of a large adverse change, measured at the 75th percentile threshold. For net wealth, we find a weakly statistically significant effect of early-stage AD on a large adverse change in net wealth ( $p < .10$  for 75th percentile change when the FHoH is afflicted).

Lastly, we examine the effect of early-stage AD on financial outcomes using the imputed probability of dementia in each wave in order to capture the level of cognitive symptoms prior to diagnosis (Panel D). We find that as cognitive symptoms (and the imputed probability of dementia) increase, the value of net wealth ( $p < .01$  for FHoH afflicted) decreases. In terms of the magnitude of the effect, the coefficients suggest a 20-percentage point increase in the probability of dementia is associated with a reduction net wealth of 13% (or \$10,867 for the median household). We further find that the probability of a large adverse change (75th or 90th percentile) in net wealth ( $p < .01$  when the FHoH is afflicted) increases as the probability of dementia increases and the effect is more pronounced when the FHoH is afflicted. The same 20 percentage point change in the probability of dementia increases the probability of a 90th percentile large adverse event by 1.6 percentage points for net wealth (when anyone in the household is afflicted). We find that as the imputed probability of dementia increases, the value of liquid assets decreases and the probability of a large adverse change in liquid assets increases, but the effects are weakly statistically significant ( $p < .10$ , when anyone in the household is afflicted). Finally, we find that the results with the ADRD only households (not shown; see Table S2) are consistent with those from the main analyses in terms of direction and magnitude of the coefficients, although we lose a degree of statistical significance.

## 4 | DISCUSSION

AD affects millions of people in the United States and tens of millions of people worldwide, exacting substantial and increasing human and monetary costs. Moreover, U.S. demographic changes suggest the prevalence of AD will increase over the next 20 years, with an estimated increase of 23% between 2010 and 2020, and a near tripling by 2050 (Alzheimer's Association, 2019). Recent studies have shown that healthcare costs and the costs of formal and informal home care attributable to dementia (of which AD is the leading cause) are roughly \$43,000–\$56,000 annually per person, translating to a total cost of \$157–\$215 billion for a single year (2010; Hurd et al., 2013a). But a full accounting of the economic costs associated with AD must recognize the contribution of the disease to poor financial outcomes during its early stage. This is important given that significant limitations and rapid declines in financial capacity are a hallmark of early-stage AD (Marson et al., 2000; Martin et al., 2008; Triebel et al., 2009) and the period between early symptoms and AD diagnosis is typically several years (Brookmeyer et al., 2002).

We find robust evidence that early-stage AD places households at significant risk for large adverse changes in liquid assets. Regardless of who in the household is afflicted, early-stage AD increases the probability of a large (90th percentile value-defined) adverse change in liquid assets by 3.3 percentage points. We find some, but more limited, evidence that early-stage AD reduces net wealth. We find that a 20% increase in the probability of dementia increases the probability

of a large adverse change in net wealth by 1.6 percentage points when anyone in the household is affected, and the effect is more pronounced when the FHoH is affected.

Several limitations are important to note. First, our findings should be interpreted as the effect of early-stage AD on financial outcomes for the subpopulation of people with diagnosed ADRD. Because we use a claims-based approach to identify individuals with dementia, our research does not speak to the effect of early-stage AD on individuals who do not receive a diagnosis. Previous research indicates claims-based diagnoses in Medicare data capture the majority (approximately 85%) of individuals with dementia (Taylor et al., 2009). We further note that our analytic sample is restricted to households in which the individual (in one adult households) or both individuals (in two adult households) can be linked to Medicare claims data. Second, the HRS relies on self-reported financial outcomes. However, to reduce nonresponse and ensure the accuracy of such data, the HRS has developed innovative methods for the collection of financial data, including the use of unfolding brackets and improvements in question ordering (Hauser & Willis, 2004). The HRS also includes a novel asset reconciliation section to ensure that changes over time in financial outcomes are real and not a result of reporting or data entry error (Moldoff et al., 2013). Additionally, it is possible that the financial information reported in the wave of diagnosis may partially reflect outcomes in the first several months following dementia diagnosis, particularly for individuals who receive a diagnosis early in the wave. However, we conducted additional sensitivity analyses in which we omitted the wave of diagnosis from analysis and our results were robust to their exclusion. We use indicator flags to identify the average window prior to diagnosis during which individuals are exposed to the early stage of the disease. Some individuals may progress faster or slower from early symptoms to diagnosis. Nonetheless, our results represent the effect of early-stage AD on financial outcomes for the average time period during which people have mild to moderate cognitive symptoms prior to diagnosis. Additionally, we provide results of sensitivity analyses in which we use an imputed measure of cognitive status. Lastly, for the large adverse change outcomes, our estimates are from fixed effect LPMs. We note that LPM estimates applied to binary outcomes are not constrained to the unit interval; such models assume a linear relationship between the covariates and the outcome; and estimation imposes heteroskedasticity in the case of binary response variable. However, we use heteroskedasticity-consistent robust standard error estimates; the assumption of linearity is arguably no more or less defensible than an assumption of nonlinearity, and alternatives such as the conditional logit estimator have the drawback that marginal effects are not easily or consistently estimated.

Our finding that early-stage AD affects households' financial outcomes is consequential for several reasons. First, these adverse changes in household financial well-being are occurring just as substantial resource demands will be placed on these families as the afflicted individual transitions into the later stage of the disease and households must grapple with the costs of years of formal and/or informal care. Second, the effects that we estimate, coupled with the high prevalence of AD among those 65 and over, suggest negative financial outcomes from compromised decision making and exploitation/fraud among those with early-stage AD is in aggregate of significant national consequence. Furthermore, these findings are important as researchers continue to make progress toward developing biomarkers that can be used to improve diagnosis of AD and develop early screening tests (Fiandaca et al., 2015, Mapstone et al., 2014, National Institute on Aging (NIA), 2019). In other contexts (such as cancer), early identification of disease facilitates timelier treatment, but in the case of AD, as described, available treatment options are extremely limited (Department of Health and Human Services, 2016). Nonetheless, earlier diagnosis may provide value to patients if it can help avert adverse financial outcomes that occur before the disease is currently diagnosable with available tools. This component of the value of early screening for and identification of AD is important for patients and payers to understand and consider when deciding whether to participate in or offer coverage for early testing, respectively. Patients will also want to consider other aspects of the utility (or disutility) of early screening and identification of AD, such as the potentially negative psychological effects of receiving bad health news, the potential for discrimination based on test results, and, on the positive side, the value of reduced uncertainty for future planning (Hall, Viney, & Haas, 1998, Liffé & Manthorpe, 2004, Billings et al., 1992, Hsu & Willis, 2013, Grosse, Wordsworth, & Payne, 2008, Shin et al., 2019).

These findings also lend support to notions forwarded by DeLiema et al. (2019), Wood and Lichtenberg (2017), and the Consumer Financial Protection Bureau (March 2016) that financial institutions can play an essential role in helping reduce exposure of vulnerable elderly to poor outcomes and that collaboration across sectors, including health, financial, and social services, may be likewise important to improving outcomes. More needs to be known about the specific financial decisions and choices that lead to reduced assets and reduced wealth during the early-stage AD period, including individuals' susceptibility to making poor financial decisions on their own and their vulnerability to the opportunism of others, so that solutions for helping to ameliorate these outcomes can be considered.

## ACKNOWLEDGEMENTS

This research was supported by the Office of the Assistant Secretary of Defense for Health Affairs, through the DoD Alzheimer's Research Program Quality of Life Research Award under Award No. W81XWH-15-PRARP-QUAL.- Opinions, interpretations, conclusions and recommendations are those of the authors and are not necessarily endorsed by the Department of Defense. The U.S. Army Medical Research Acquisition Activity, 820 Chandler Street, Fort Detrick MD 21702-5015 is the awarding and administering acquisition office. The sponsor had no role in study design, collection/analysis/interpretation of data, writing of the manuscript, or decision to submit for publication.

## CONFLICT OF INTEREST

Drs. Gresenz, Mitchell, and Marrone declare no conflicts of interest. Dr. Federoff's research includes work to develop blood tests that can be used to predict who will develop Alzheimer's disease; he has filed patents on these blood tests.

## HUMAN SUBJECTS PROTECTION

This study received IRB approval from the RAND Human Subjects Protection Committee (HSPC ID 2016-0395) and from the United States Army Medical Research and Materiel Command (USAMRMC), Office of Research Protections (ORP), Human Research Protection Office (HRPO; HRPO Assigned Number: A-19817).

## ORCID

Carole Roan Gresenz  <https://orcid.org/0000-0002-7381-7914>

Jean M. Mitchell  <https://orcid.org/0000-0002-2765-4624>

Howard J. Federoff  <https://orcid.org/0000-0002-7595-6520>

## REFERENCES

- Agarwal, S., & Mazumder, B. (2013). Cognitive abilities and household financial decision making. *American Economic Journal: Applied Economics*, 5(1), 193–207.
- Alzheimer's Association (2019). 2019 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 15(3), 321–387.
- Angrist, J. D., & Pischke, J.-S. (2009). *Mostly Harmless Econometrics*. Princeton, NJ: Princeton University Press.
- Becker, G. S. (1993). *A Treatise on the Family*. Cambridge, MA: Harvard University Press.
- Billings, P. R., Kohn, M. A., De Cuevas, M., Beckwith, J., Alper, J. S., & Natowicz, M. R. (1992). Discrimination as a consequence of genetic testing. *American Journal of Human Genetics*, 50(3), 476.
- Brookmeyer, R., Corrada, M. M., Curriero, F. C., & Kawas, C. (2002). Survival following a diagnosis of Alzheimer disease. *Archives of Neurology*, 59(11), 1764–1767.
- Burbidge, J. B., Magee, L., & Robb, A. L. (1988). Alternative transformations to handle extreme values of the dependent variable. *Journal of the American Statistical Association*, 83(401), 123–127.
- Burnes, D., Henderson, C. R. Jr., Sheppard, C., Zhao, R., Pillemer, K., & Lachs, M. S. (August 1, 2017). Prevalence of financial fraud and scams among older adults in the United States: a systematic review and meta-analysis. *American Journal of Public Health*, 107(8), e13–e21.
- CMS. (2017). Chronic Conditions Data Warehouse (CCW): Chronic Condition Algorithms. Retrieved from <https://www.ccwdata.org/web/guest/condition-categories>
- Consumer Financial Protection Bureau, Recommendations and report for financial institutions on preventing and responding to elder financial exploitation, March 2016.
- Consumer Financial Protection Bureau, Financial institutions report widespread elder financial abuse (Karp, N, and Ortiz H), Feb 27, 2019, <https://www.consumerfinance.gov/about-us/blog/financial-institutions-report-widespread-elder-financial-abuse/>, .
- Consumer Fraud Research Group. (2006). Investor fraud study final report. Washington, DC: Prepared for WISE Senior Services and the NASD Investor Education Foundation, Consumer Fraud Research Group.
- DeLiema, M., Deevy, M., Lusardi, A., & Mitchell, O. S. (2019). Financial Fraud among older Americans: evidence and implications. *Journals of Gerontology: Social Sciences*, XX(XX), 1–8.
- Department of Health and Human Services (2016). Alzheimer's disease fact sheet. Retrieved from <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet#symptoms>
- Fiandaca, M., Zhong, X., Cheema, A. K., Orquiza, M. H., Chidambaram, S., Tan, M. T., ... Federoff, H. J. (2015). Plasma 24-metabolite panel predicts preclinical transition to clinical stages of Alzheimer's disease. *Frontiers in Neurology*, 6, 237.

- Greene, W. (2004). The behavior of the maximum likelihood estimator of limited dependent variable models in the presence of fixed effects. *The Econometrics Journal*, 7(1), 98–119.
- Grinblatt, M., Keloharju, M., & Linnainmaa, J. (2012). IQ, trading behavior, and performance. *Journal of Financial Economics*, 104, 339–362.
- Grosse, S. D., Wordsworth, S., & Payne, K. (2008). Economic methods for valuing the outcomes of genetic testing: beyond cost-effectiveness analysis. *Genetics in Medicine*, 10(9), 648–654.
- Hall, J., Viney, R., & Haas, M. (1998). Taking a count: the evaluation of genetic testing. *Australian and New Zealand Journal of Public Health*, 22(7), 754.
- Hauser, R. M., & Willis, R. J. (2004). Survey design and methodology in the Health and Retirement Study and the Wisconsin Longitudinal Study. *Population and Development Review*, 30 Supplement: Aging, Health, and Public Policy, 209–235.
- HRS, I. f. S. R., University of Michigan. (2013). Aging, Demographics, and Memory Study (ADAMS) Supplement: Data Release (v. 8.0): Data Description and Usage for Tracker, Wave A, Wave B, Wave C, Wave D. Retrieved from Ann Arbor, MI:
- HRS, I. f. S. R., University of Michigan. (2016). Restricted data overview: HRS/CMS research data. Retrieved from <http://hrsonline.isr.umich.edu/index.php?p=medicare>
- Hsu, J. W., & Willis, R. (2013). Dementia risk and financial decision making by older households: the impact of information. *Journal of Human Capital*, 2013, 45.
- Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013a). Monetary costs of dementia in the United States. *New England Journal of Medicine*, 368(14), 1326–1334.
- Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013b). Supplementary appendix: monetary costs of dementia in the United States. *New England Journal of Medicine*, 368(14), 1326–1334.
- Joyce, A. T., Zhao, Y., Bowman, L., Flynn, J. A., Carter, C. T., & Ollendorf, D. A. (2007). Burden of illness among commercially insured patients with Alzheimer's disease. *Alzheimer's & Dementia*, 3(3), 204–210.
- Judges, R. A., Gallant, S. N., Yang, L., & Lee, K. (2017). The role of cognition, personality, and trust in fraud victimization in older adults. *Frontiers in Psychology*, 8, 588. <https://doi.org/10.3389/fpsyg.2017.00588>
- Konetzka, R. T., & Luo, Y. (2011). Explaining lapse in long-term care insurance markets. *Health Economics*, 20(10), 1169–1183.
- Konetzka, R. T., Stuart, E. A., & Werner, R. M. (2018). The effect of integration of hospitals and post-acute care providers on Medicare payment and patient outcomes. *Journal of Health Economics*, 61, 244–258.
- Lliffe, S., & Manthorpe, J. (2004). Editorial: The hazards of early recognition of dementia: a risk assessment. *Aging & Mental Health*, 8(2), 99–105.
- Mapstone, M., Cheema, A. K., Fiandaca, M. S., Zhong, S., Zhong, X., Mhyre, T. R., ... Haley, J. M. (2014). Plasma phospholipids identify antecedent memory impairment in older adults. *Nature Medicine*, 20(4), 415–418.
- Marson, D. C., Sawrie, S. M., Snyder, S., McInturff, B., Stalvey, T., Boothe, A., ... Harrell, L. E. (2000). Assessing financial capacity in patients with Alzheimer disease: a conceptual model and prototype instrument. *Archives of Neurology*, 57(6), 877–884.
- Martin, R. C., Griffith, H. R., Belue, K., Harrell, L., Zamrini, E., Anderson, B., ... Marson, D. (2008). Declining financial capacity in patients with mild Alzheimer disease: a one-year longitudinal study. *The American Journal of Geriatric Psychiatry*, 16(3), 209–219.
- Martin, R. C., Triebel, K. L., Kennedy, R. E., Nicholas, A. P., Watts, R. L., Stover, N. P., ... Marson, D. C. (2013). Impaired financial abilities in Parkinson's disease patients with mild cognitive impairment and dementia. *Parkinsonism & Related Disorders*, 19(11), 986–990.
- Marton, J., Yelowitz, A., & Talbert, J. C. (2014). A tale of two cities? The heterogeneous impact of Medicaid managed care. *Journal of Health Economics*, 36, 47–68.
- McArdle, J. J., Smith, J. P., & Willis, R. (2011). Cognition and economic outcomes in the health and retirement survey. In D. A. Wise (Ed.), *Explorations in the Economics of Aging*. Chicago, IL: University of Chicago Press.
- Moldoff M, Meijer E, Chien, S, Hayden O, Hurd M, Main, R, ... St. Clair P (2013). RAND HRS income and wealth imputation, Version M. Rand Center for the Study of Aging.
- National Center on Elder Abuse, <https://ncea.acl.gov/FAQ.aspx>, last accessed May 17, 2019.
- National Institute on Aging (NIA), Biomarkers for dementia detection and research, <https://www.nia.nih.gov/health/biomarkers-dementia-detection-and-research>, last accessed May 17, 2019.
- Neyman, J., & Scott, E. (1948). Consistent estimates based on partially consistent observations. *Econometrica*, 16(1), 1–32.
- Okonkwo, O. C., Wadley, V. G., Griffith, H. R., Belue, K., Lanza, S., Zamrini, E. Y., ... Raman, R. (2008). Awareness of deficits in financial abilities in patients with mild cognitive impairment: going beyond self-informant discrepancy. *The American Journal of Geriatric Psychiatry*, 16(8), 650–659.
- Pence, K. M. (2006). The role of wealth transformations: an application to estimating the effect of tax incentives on saving. *The BE Journal of Economic Analysis & Policy*, 5(1).
- Petersen, R. C., Smith, G. E., Waring, S. C., Ivnik, R. J., Tangalos, E. G., & Kokmen, E. (1999). Mild cognitive impairment: clinical characterization and outcome. *Archives of Neurology*, 56(3), 303–308.
- Salm, M. (2009). Does job loss cause ill health? *Health Economics*, 18(9), 1075–1089.

- Shin SH, Lillard DR, Bhattacharya J. Understanding the correlation between Alzheimer's disease polygenic risk, wealth, and the composition of wealth holdings, NBER Working Paper 25526 <http://www.nber.org/papers/w25526>, February 2019, Cambridge MA.
- Stiegel, L. A. (2012). An overview of elder financial exploitation. *Generations*, 36, 73–80.
- Taylor, D. H., Fillenbaum, G. G., & Ezell, M. E. (2002). The accuracy of Medicare claims data in identifying Alzheimer's disease. *Journal of Clinical Epidemiology*, 55(9), 929–937.
- Taylor, D. H., Østbye, T., Langa, K. M., Weir, D., & Plassman, B. L. (2009). The accuracy of Medicare claims as an epidemiological tool: the case of dementia revisited. *Journal of Alzheimer's Disease*, 17(4), 807–815.
- Triebel, K., Martin, R., Griffith, H., Marceaux, J., Okonkwo, O., Harrell, L., ... Marson, D. (2009). Declining financial capacity in mild cognitive impairment: a 1-year longitudinal study. *Neurology*, 73(12), 928–934.
- Wood, S., & Lichtenberg, P. A. (2017). Financial capacity and financial exploitation of older adults: research findings, policy recommendations and clinical implications. *Clinical Gerontologist*, 40(1), 3–13. <https://doi.org/10.1080/07317115.2016.1203382>

## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**How to cite this article:** Gresenz CR, Mitchell JM, Marrone J, Federoff H. Effect of early-stage Alzheimer's disease on household financial outcomes. *Health Economics*. 2019;1–12. <https://doi.org/10.1002/hec.3962>

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## Heightened Risk of Adverse Financial Changes Before Alzheimer's Diagnosis



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### Media Contact:

Karen Teber

[km463@georgetown.edu](mailto:km463@georgetown.edu)

**WASHINGTON (October 25, 2019)** — Prior to an Alzheimer's diagnosis, a person in the early stages of the disease faces a heightened risk of adverse financial outcomes — a likely consequence of compromised decision-making when managing money, in addition to exploitation and fraud by others.

That is the disquieting conclusion of a [study published in the journal \*Health Economics\*](#).

Alzheimer's disease isn't usually diagnosed until symptoms are severe, and its progression typically involves a multi-year process of cognitive decline.

"Previous studies show that people in the very early stages of Alzheimer's lose financial capacity; that is, their ability to manage their checkbook, to pay bills on time, to spend in ways that are consistent with the values they had in the past," explains the study's lead author, health economist Carole Roan Gresenz, PhD, interim dean for Georgetown University's School of Nursing & Health Studies.

In the study, Gresenz and her colleagues wanted to know more about that impact. "What happens to financial household outcomes during that period of cognitive decline prior to diagnosis?"

To find the answer, the researchers merged data from two sources: the Health and Retirement Study and Medicare claims.

The Health and Retirement Study is a nationally representative, longitudinal survey of Americans over the age of 50 sponsored by the National Institute on Aging, which includes questions about households' financial assets and liabilities. The Medicare data allow the researchers to identify individuals who have been diagnosed with Alzheimer's disease or related dementia as well as the date of diagnosis.

"These combined data allow us to track backwards from the date of diagnosis to figure out what was happening to households financially prior to diagnosis," Gresenz explains.

"What we found was that households in which someone is in the early stage of the disease are vulnerable to large reductions in liquid assets, such as savings, money market and checking accounts," she says.

The team also found evidence that these households are likely to have a reduction in net wealth during that time period.

"The findings are concerning, because these adverse financial outcomes are occurring just prior to when substantial resource demands will be placed on these families as they grapple with costs related to caregiving needs," Gresenz says.

She says the findings also speak to the potentially important role of financial institutions in reducing the exposure of vulnerable elderly to poor outcomes.

The researchers are now working on matching credit data — which includes more granular financial outcomes measured for more refined time periods — with Medicare data.

"We want to understand more about the specific types of financial decisions and choices that underlie these findings, as well as to explore whether financial information offers the potential for early identification of individuals who are in the initial stages of Alzheimer's disease and who should be prioritized for additional clinical screening," she says.

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In addition to Gresenz, study authors include Jean M. Mitchell, PhD, of Georgetown's McCourt School of Public Policy, James Marrone, PhD, of RAND, and Howard Federoff, MD, PhD, of University of California, Irvine.

This work was supported by the Office of the Assistant Secretary of Defense for Health Affairs, through the DoD Alzheimer's Research Program Quality of Life Research Award (W81XWH-16-1-0746). Opinions, interpretations, conclusions and recommendations are those of the authors and are not necessarily endorsed

by the Department of Defense. The U.S. Army Medical Research Acquisition Activity, 820 Chandler Street, Fort Detrick, MD 21702-5014 is the awarding and administering acquisition office.

Gresenz, Mitchell and Marrone report having no personal financial interests related to the studies. Federoff's research includes work to develop blood tests that can be used to predict who will develop Alzheimer's disease; he has filed patents on these blood tests.



## Georgetown University Medical Center

4000 Reservoir Road, NW

Washington, D.C.

Phone: **(202) 687-0100**

Email: [gumccomm@georgetown.edu](mailto:gumccomm@georgetown.edu)

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## Appendix 3: Bibliography, Meeting Abstracts, List of Personnel

### Bibliography

Gresenz CR, Mitchell JM, Marrone J, Federoff H. Effect of early-stage Alzheimer's disease on household financial outcomes. *Health Economics*. 2019;1–20. <https://doi.org/10.1002/hec.3962>

### Meeting Abstracts

*Effect of early stage Alzheimer's Disease on Household Financial Outcomes: Work in Progress* Georgetown University Population Health and Health Services Research Seminar Series, September 19, 2018.

Abstract: Significant limitations and rapid declines in financial capacity are a hallmark of patients with early stage Alzheimer's disease (AD). We use linked Health and Retirement Study (HRS) and Medicare claims data to examine the effect of early stage AD and related disorders, from the start of first symptoms to diagnosis of dementia, on household financial outcomes. We find that early stage AD place households at significant risk for large adverse changes in liquid assets and net wealth, and that this finding is robust to a number of sensitivity analyses. Our findings are consequential because vulnerabilities during early stage AD in turn impact the ability of individuals and their families to pay for many years of necessary care. Furthermore, the magnitudes of the effects that we estimate, coupled with the high prevalence of AD among those 65 and over, suggest negative financial outcomes from compromised decision-making and exploitation among those with early stage AD is in aggregate of significant national consequence.

*Effect of early stage Alzheimer's Disease on Household Financial Outcomes: Work in Progress*, RAND Health seminar series, November 6, 2018.

Abstract (Same as Above): Significant limitations and rapid declines in financial capacity are a hallmark of patients with early stage Alzheimer's disease (AD). We use linked Health and Retirement Study (HRS) and Medicare claims data to examine the effect of early stage AD and related disorders, from the start of first symptoms to diagnosis of dementia, on household financial outcomes. We find that early stage AD places households at significant risk for large adverse changes in liquid assets and net wealth, and that this finding is robust to a number of sensitivity analyses. Our findings are consequential because vulnerabilities during early stage AD in turn impact the ability of individuals and their families to pay for many years of necessary care. Furthermore, the magnitudes of the effects that we estimate, coupled with the high prevalence of AD among those 65 and over, suggest negative financial outcomes from compromised decision-making and exploitation among those with early stage AD is in aggregate of significant national consequence.

### List of Personnel

- Carole Roan Gresenz (PI), RAND and Georgetown University

- James Marrone (Co-investigator), RAND
- Jean Mitchell (Co-investigator), Georgetown University
- Howard Federoff (Consultant), University of California, Irvine
- Aaron Kofner (Programmer), RAND
- Caitlin Chamberlain (Research assistant), Georgetown University