Caregiving for Dementia and the Medicare Expenditures of Spouses of Persons with Dementia

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Abstract

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Over 6.7 million Americans are living with Alzheimer's Disease and Related Dementias and this population of persons living with dementia (PLWD) is projected to double in the next 30 years. This means that demand for dementia care and costs associated with the condition will also be increasing over this period. PLWD require a substantial amount of formal medical care, an estimated $345 billion of direct costs in 2023, and they also need a large amount of day-to-day help provided by family and friends as caregivers. While there are some benefits to caregiving, having a household member with dementia, especially a spouse, can result in significant strains that translate to worse health outcomes, greater healthcare utilization, and higher healthcare expenditures.

This dissertation uses data from the Health and Retirement Study linked to Medicare claims to quantitatively answer questions related to gaps in literature on dementia. Major findings include: PLWD have a significant increase (nearly double) in receiving caregiving for activities of daily living before and after dementia onset; certain PLWD subpopulations (Black PLWD, PLWD with lower educational attainment, PLWD with no private health insurance) are less likely to receive help with ADLs or IADLs even after controlling for difficulty with ADLs, IADLs, and co-occurring chronic conditions; spouses of PLWD incurred, on average, $2,748 higher Medicare Part A & B expenditures in the fifth year post dementia onset compared to their no dementia counterparts; spouses of PLWD incurred significantly higher expenditures, $6,315, than spouses with of partners with no dementia in the year leading up to partner death.

This body of work contributes important quantitative contributions to the dementia care literature, in regard to the caregiving needs of PLWD pre- and post- dementia onset and to the indirect costs of dementia on PLWD spouse’s health care spending.

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Chapter 1. INTRODUCTION

One in nine adults aged 65 years and older in the United States are living with Alzheimer's Disease and Related Dementias, which represents 6.7 million Americans in 2023.[1] Recent studies have shown that the age-adjusted dementia prevalence and incidence is remaining constant or in decline.[2,3] However, the proportion of the population with dementia is still expected to increase from 6.1% in 2020 to 13.8% in 2060 simply due to sheer size of the population entering this 65 years and older demographic group.[1,4] This means that demand for dementia care and costs associated with the condition will also be increasing over this period.

1.1 COSTS OF DEMENTIA CARE

In 2023, the total costs of care for PLWD were estimated to be $345 billion dollars.[1] Nearly half (45%) was covered by Medicare, but while Medicaid paid for a some of the remaining costs of care, substantial expenses was borne out-of-pocket by people living with dementia (PLWD) or their families, along with private insurance as well as care that was simply uncompensated. These estimated costs are for formal care such as: inpatient and outpatient services, home health services, skilled nursing facilities, hospice, and long-term care facilities like nursing homes. Medicare covers the first two services with Part A and Part B respectively, and some home health and skilled nursing services under certain conditions, but beyond that scope of services financial coverage is unreliable. Medicare and some other forms of insurance cover the medical costs of dementia, but it does not cover the day-to-day help that PLWD need.

In 2022, unpaid caregivers provided 18 billion hours of care for PLWD, valued at $339.5 billion.[1] This amount is not paid to these caregivers, rather this is the estimated value of indirect dementia costs family members and friends of PLWD are paying for with their uncompensated time. Family caregiving includes helping with activities of daily living (ADLs), instrumental activities of daily living (IADLs), as well as filling a role of a health monitor and medical care coordinator, an emotional supporter, a manager of behavioral symptoms and more.[1,5] For PLWD in the community, nearly one-third rely on three or more family caregivers, while over two-thirds are relying on just one or two family caregivers to help with these types of tasks.[6]

1.2 IMPACT ON FAMILIES & CAREGIVERS

There are benefits of providing caregiving to the unpaid caregiver such as skill-building, satisfaction in caregiving for another, and continuing to be close to a loved one.[1,7,8] However, providing care for dementia can be quite strenuous, even compared to caregiving for other conditions.[1,5] These conditions can result in other indirect costs of dementia care. Those that are providing caregiving may need to leave their work, or work fewer hours, so there is an indirect cost in the form of lost income to the household.[9] This reduction in time, income and other household resources can be further exacerbated by the out-of-pocket costs of formal care for the PLWD, as well as the cost of changes in housing or implementing safety features in the home, transportation for medical appointments, and hiring help to coordinate legal and financial affairs.[9] . This can translate to household or caregiver's depletion of savings, food insecurity, medication rationing, and delaying medical care. The impacts of financial strain along with the general stress from working as a caregiver can result in worse physical and mental health.[1,5] Altogether, these factors can impact health, healthcare utilization, and healthcare expenditures of caregivers and household members of PLWD,[10] resulting in another kind of indirect cost of dementia.

1.3 OVERVIEW OF AIMS

The studies summarized in the next three chapters attempt to fill in some of the gaps in the dementia literature. Chapter 2 examines types of dementia caregiving and characteristics of caregivers pre- and post- dementia onset, as well as identifying predictors of receiving family caregiving just after dementia onset. Chapter 3 and 4 both focus on a specific type of a potential indirect cost of dementia, that of spouse Medicare expenditures after their partner's onset. Chapter 3 does a simple comparison 5 years after dementia onset, while Chapter 4 examines Medicare costs of spouses around their partner's time of death, within same 5-year follow-up. Chapter 5 summarizes this body of work's contribution to dementia literature.

Chapter 2. CAREGIVING FOR DEMENTIA: TRENDS PRE-POST ONSET AND PREDICTIVE FACTORS OF FAMILY CAREGIVING (2000-2018)

2.1 BACKGROUND

Persons living with Alzheimer's and other related forms of Dementia (PLWD) often require significant caregiving leading up to and during disease onset.[1] As dementia progresses, greater help is needed with both instrumental activities of daily living (IADLs), such as grocery shopping and managing prescriptions, as well as functional activities of daily living (ADLs), such as getting dressed and bathing.[1] The largest increase in help is at dementia onset (Figure 2.1).

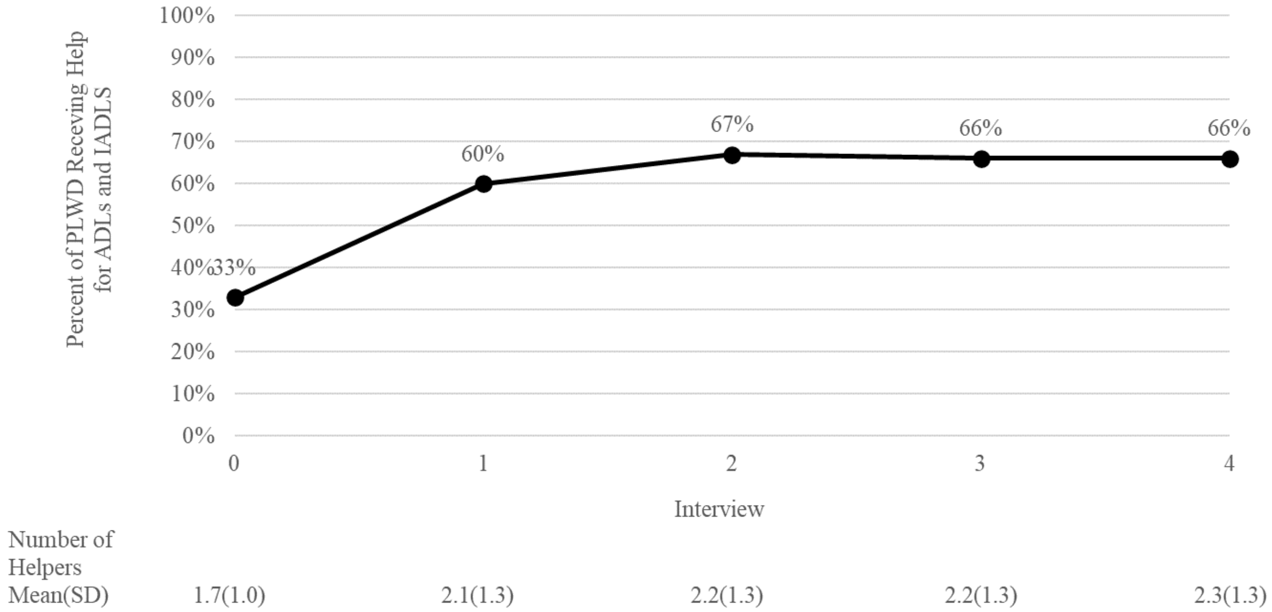


Figure 2.1. Percent of Population Receiving Help for ADLs and IADLs Pre and Post Dementia Onset.

Caption: Authors' analysis of data from the Health and Retirement Study, 2002-2018. PLWD-Persons Living with Dementia; ADLs-Activities of Daily Living; IADLs-Instrumental Activities of Daily Living; SD-Standard Deviation. Participants could report multiple helpers, and a variety of characteristics for each helper, such as the relationship of the helper and whether they are paid. Population includes all PLWD with complete survey or exit interview information, even those that did not report difficulties.

Most insurance plans in the United States do not cover support with daily activities; instead, this is often provided through unpaid help by family members and friends.[11] Alternatively, some support is provided in long term care facilities or from professional caregivers visiting the home.[6] When formal care is used, it typically incurs an out-of-pocket cost unless that person has long-term care insurance, or they are eligible for Medicaid or Veterans Affairs benefits. As a result, the resources devoted to these services are not captured in traditional health care databases such as claims or medical records.

Most of the extant research on caregiving for PLWD is based on prevalent disease and little is known about the role of family caregiving before dementia onset and as the condition progresses.[12–14] To our knowledge only two previous studies have examined caregiving and caregiver characteristics longitudinally, and they found that numbers of caregivers and hours of caregiving increased from onset to 8 years post-onset.[15,16] We extend this research to include the pre onset period to examine how these critical caregiving patterns initiate. We summarize characteristics of PLWD and their caregivers to describe caregiving that PLWD receive before the onset of dementia and up to six years post onset. We also predict receipt of family care during the onset interview based on information from the interview prior to dementia onset.

2.2 METHODS

2.2.1 *Data Sources*

We use data from the Health and Retirement Study (HRS), a biennial longitudinal survey of approximately 20,000 older adults and their spouses conducted since 1992.[17] We combined a respondent's first positive screen for dementia with information from the prior interview and up to three interviews after the first positive interview. The HRS has a robust process for including proxy responses if respondents have limited capacity to answer questions due to health or cognitive issues and those proxy responses were included in this study.[17] This study uses data from 2000 to 2018, when survey questions regarding caregiving were consistent.

2.2.2 *Study Population*

Survey participants were included in the sample if they had their first positive dementia screen from 2002-2018 based on the Langa-Wier Classifications.[18] Participants with a positive dementia screen were excluded if they were less than 50 years old, or if their spouse also had a positive screen for dementia during that interview or during a prior interview. The final sample included 2,706 HRS participants with dementia.

2.2.3 *Outcomes*

The primary outcome for receiving family care was defined as the respondent or their proxy reporting that: 1) they had difficulty with at least one ADL or IADL, 2) they received help for an ADL or IADL, and, 3) they report information about at least one helper that was a family member or friend, rather than paid or professional care. For respondents that died and did not respond to interview request, the exit interview information was used to report on nursing home information, receiving help for ADLs and IADLs, caregiving frequency, and caregiver attributes.

2.2.4 *Statistical Approach*

We provide sociodemographic characteristics for PLWD, their utilization of nursing homes facilities, and characteristics of the care they received before and after their first positive screen. Further, we model the probability of receiving family care during the onset interview as a function of information from the previous interview using logistic regression. Full methodological details are in Appendix A.

2.3 RESULTS

Figure 2.2 reports caregiving changes over time and average number of helpers for those receiving help. The biggest increase in receiving help occurred between the interview prior to onset and onset, with the proportion of those receiving any help for ADLs and/or IADLs increasing from 33% to 60%. In the onset interview, 94.7% of those receiving help received at least some family caregiving, and this proportion remained consistent in subsequent interviews. The mean and standard deviation (SD) number of helpers is 2.1(SD=1.3) at the onset interview, with small increases over time. Appendix B and C has more detailed data on primary caregivers and breaks caregiving down by type of activity.

Table 2.1 summarizes demographic information for the entire population, stratified by receipt of family care during the first positive dementia interview. Those receiving family care were slightly older, had difficulty with a greater number of IADLs and ADLs, were more likely to be insured, and to identify as Non-Hispanic and White (see Appendix D for details).

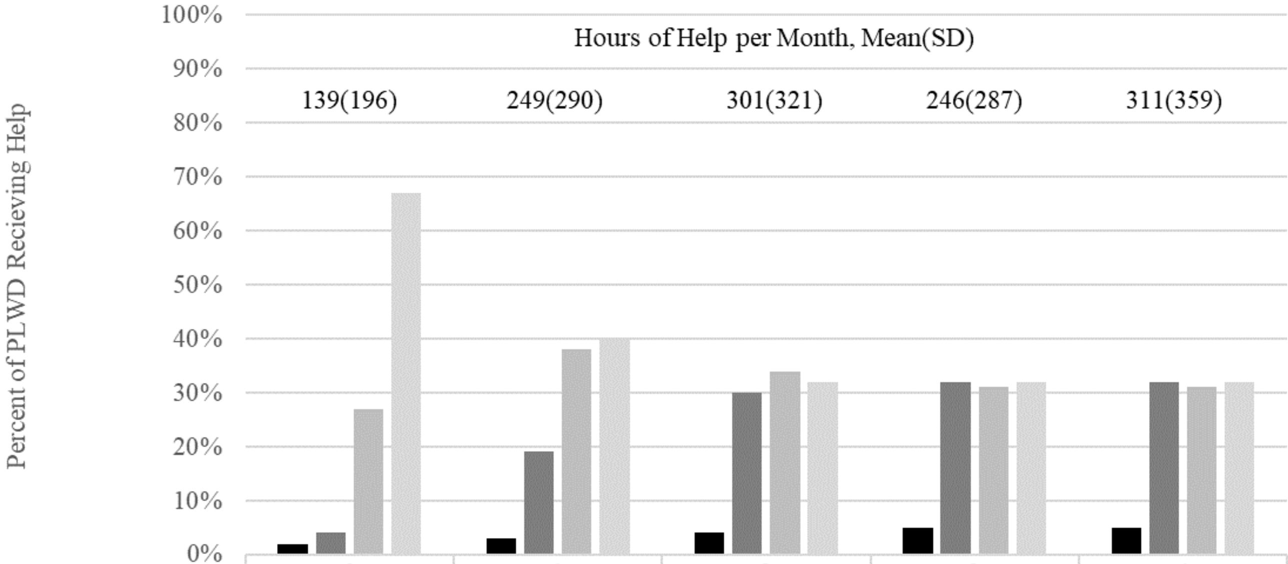
Table 2.1. Dementia Population Demographics by Receipt of Family Care at Onset Interview

	All PLWD		Not Receiving Family Care		Receiving Family Care		
Characteristics of PLWD	n=	2706	n=	1168	n=	1538	Difference*
Age, mean (SD)	78.0	11.0	75.2	11.1	80.0	(10.4)	4.8
Male, n %	1060	39.2%	458	39.2%	602	39.1%	-0.1%
Married, n %	1134	41.9%	469	40.2%	665	43.2%	3.1%
White, n %	1954	72.2%	750	64.2%	1204	78.3%	14.1%
Black/African American, n %	558	20.6%	312	26.7%	246	16.0%	-10.7%
Other Race, n %	194	7.2%	106	9.1%	88	5.7%	-3.4%
Hispanic, n %	380	14.0%	200	17.1%	180	11.7%	-5.4%
Less than High School, n %	1037	38.3%	515	44.1%	522	33.9%	-10.2%
High School or GED, n %	921	34.0%	390	33.4%	531	34.5%	1.1%
Some College or More, n %	748	27.6%	263	22.5%	485	31.5%	9.0%
Working for Money, n %	159	5.9%	133	11.4%	26	1.7%	-9.7%
Number of Chronic Conditions, mean (SD)	3.0	1.6	2.5	1.5	3.4	1.5	0.9
Medicare, n %	2334	86.3%	943	80.7%	1391	90.4%	9.7%
Medicaid, n %	562	20.8%	221	18.9%	341	22.2%	3.3%
Private Health Insurance Plan, n %	973	36.0%	348	29.8%	625	40.6%	10.8%
Long Term Care Insurance, n %	261	9.6%	76	6.5%	185	12.0%	5.5%
Life Insurance, n %	1236	45.7%	514	44.0%	772	50.2%	6.2%
Number of ADLs with Some Difficulty, mean (SD)	1.7	2.2	0.5	1.2	2.7	2.2	2.2
Number of IADLs with Some Difficulty, mean (SD)	1.9	1.9	0.3	0.8	3.2	1.6	2.9

No Living Children, n %	202	7.5%	107	9.2%	95	6.2%	-3.0%
Proxy, n %	880	32.5%	60	5.1%	820	53.3%	48.2%

Authors' analysis of data from the Health and Retirement Study, 2002-2018. [*Differences Receiving Family Care - Not Receiving Family Care. PLWD-Persons Living with Dementia; ADLs-Activities of Daily Living; IADLs-Instrumental Activities of Daily Living; SD-Standard Deviation.

Figure 2.2 depicts types of care received (formal help only, family help only, combination help, no help) over the study period with hours of help received for each. There is a large increase in help received and hours of help during onset and a modest increase in the first 2 years, but there is little change in the type and hours of support in the following years (see Appendix E for details).



	0	1	2	3	4
■ Formal Help Only	2%	3%	4%	5%	5%
■ Combination Help	4%	19%	30%	32%	32%
■ Family Help Only	27%	38%	34%	31%	31%
■ No Help	67%	40%	32%	32%	32%

Figure 2.2. Proportion of PLWD Population Receiving Help Pre and Post Dementia Onset; Number of Hours per Month of Help Received Pre and Post Dementia Onset.

Caption: Authors' analysis of data from the Health and Retirement Study, 2002-2018. PLWD-Persons Living with Dementia; SD-Standard Deviation. Summary statistics presented as bars include all PLWD with complete survey or exit interview information, even those that did not report difficulties. Summary statistics on hours only include those that reported at least 1 helper and had complete hourly data on all the helpers they reported.

Table 2.2 shows that by the first post onset interview the mortality rate was 35.4%, and this increased to 52.7% by the third post interview (approximately 6 years after onset). In post interviews, those surviving were more likely to have stays in nursing homes and for those stays to be longer. Appendix F has more detailed information on mortality, loss to follow-up, and nursing home utilization over time.

Table 2.2. Mortality and Nursing Home Utilization Pre and Post Dementia Onset

	Interview 0 (-2 years)		Interview 1 (Onset)		Post Interview 1 (+ 2 years)		Post Interview 2 (+4 years)		Post Interview 3 (+ 6 years)	
	n=	2706	n=	2706	n =	2706	n=	2706	n=	2706
Cohort Mortality, n%	0	0.0%	0	0.0%	959	35.4%	1262	46.6%	1426	52.7%
Surviving Population with NH Utilization data	n=	2706	n=	2683	n=	1709	n=	999	n=	580
Any Time in a NH Since Last Interview, n %	264	9.8%	704	26.2%	569	33.3%	349	34.9%	210	36.2%
Currently in a NH as of Interview/at Death, n %	106	3.9%	475	17.7%	437	25.6%	293	29.3%	167	28.8%
Number of Nights in NH since last interview*, n%										
1-90 Nights	144	54.5%	296	42.0%	174	30.6%	76	21.8%	48	22.9%
91-180 Nights	26	9.8%	66	9.4%	31	5.4%	20	5.7%	11	5.2%
181-365 Nights	24	9.1%	73	10.4%	48	8.4%	40	11.5%	14	6.7%
>365 Nights	50	18.9%	218	31.0%	275	48.3%	183	52.4%	118	56.2%
Missing	20	7.6%	51	7.2%	41	7.2%	30	8.6%	19	9.0%

Authors' analysis of data from the Health and Retirement Study, 2002-2018. *Conditional on any time in a nursing home. NH-Nursing Home. Summary statistics presented include all Persons Living with Dementia with complete survey or exit interview information, even those that did not report difficulties.

There were multiple factors before onset that significantly predicted receiving family care during the onset interview (Table 2.3). Those receiving help in the prior interview with household chores and those already receiving family care for ADLs and IADLs were more likely to receive family care in the onset interview. White PLWD were more likely (7.3 percentage points) to be receive family care during their onset interview than Black and African American PLWD. Those with greater education levels and private insurance were more likely to receive family care. A greater number of chronic conditions and number of difficult IADLs reported in the prior interview also predicted greater likelihood of receiving family care during the onset interview. The full regression analysis specification and output are in Appendix G.

Table 2.3. Regression Generated Predicted Probabilities of Receiving Family Care during Onset Interview based on Factors from the Prior Interview

Persons living with Dementia Characteristics Prior to Onset	Percentage Point Difference Estimate	95% Confidence Interval	p-value
Race			
Race White/Caucasian	7.3	[2.5, 12.1]	0.003
Race Other	4.4	[-3.7, 12.6]	0.285
Black/African American (reference = 51.7%)	-		
Level of Education			
Some College or More	8.5	[3.8, 13.2]	<0.001
GED or High School	5.0	[0.8, 9.2]	0.021
Less than High School (reference = 52.8%)	-		
Private Health Insurance?			
Yes	4.4	[0.7, 8.1]	0.020
No (reference = 55.0%)	-		
Receiving Help with Chores or Yardwork?			
Yes	7.9	[4.0, 11.8]	<0.001
No (reference = 54.3%)	-		
Currently Receiving Family Care?			
Yes	19.6	[13.8, 25.4]	<0.001
No (reference = 51.8%)	-		
Years of age	0.6	[0.4, 0.8]	<0.001
Number of Chronic Conditions	2.7	[1.5, 3.9]	<0.001
Number of IADL Limitations	6.6	[3.8, 9.4]	<0.001

Authors' analysis of data from the Health and Retirement Study, 2002-2018. For categorical characteristics, like race, the difference estimate refers to the percentage point difference in predicted probability of receiving family care compared to reference category's rate of receiving family care. For continuous or counted variables, like age, the difference is the percentage point difference in predicated probability associated with a single unit increase, such as one year. The logistic regression model adjusted for age, gender, race, ethnicity, education level, marital status, income and wealth quartiles, working status, number of chronic conditions, health insurance type, long term care insurance, life insurance, difficulty with ADLs or IADLS, receiving family care, nursing home status, number of living children, friends nearby (within 10 miles), future help expectations, receiving help with yard work or chores. For odds ratios and complete regression output see Appendix G.

2.4 DISCUSSION

We found that a third of people living with dementia were receiving help with daily activities prior to their first positive dementia screen; this increased to 60% during the first positive screen and persisted in subsequent years. Nearly all of those receiving help were receiving care from family members, with nearly a third receiving both family and formal help with ADLs or IADLs. These results demonstrate the large and growing demand for family caregiving, and that support services to help caregivers, like those provided in Medicare's new dementia care model, will also be in high demand.[19]

This study expands the literature of caregiving trends for PLWD by examining the critical point before dementia onset in addition to the years after, giving insight into how caregiving evolves over time. Estimates of family caregiving rates after onset from our study are slightly lower compared to previous studies, likely due to our more inclusive study population (i.e., younger) and our longitudinal study design.[12,15]

We also examined the relationship between characteristics of PLWD prior to dementia onset and receipt of family caregiving after onset. Higher education, along with having more comorbidities and more difficulties with IADLs predicted higher rates of caregiving. We also found that White PLWD were more likely than Black PLWD to receive any family caregiving. This result differs from that of Friedman (2015), which found that Black PLWD were more likely to receive intense family caregiving, defined as more than 200 hours per month.[12,16] The differences in results is likely caused by the definition of family care (receiving any family care versus intense family care).

2.4.1 *Strengths and Limitations*

Due to the study being focused on time relative to onset, the HRS survey design and weights are not used in our analysis, thus this is not nationally representative. HRS data is highly reliant on self-report and proxy reports, and the switch from self-report to proxy likely co-occurs with cognitive decline. Because of this co-occurrence there may be extra variation in reporting around our time of predictive interest.

Our data on caregiving is limited to those reporting difficulties with ADLs and IADLs. These are common measures that indicate physical and cognitive limitations and are a strong predictor of the need for both family and formal caregiving. However, these are not the only limitations that may require caregiving, and caregiving may be needed for reasons not related to limitations, such as care coordination and emotional support.[14] Therefore, our caregiving measures likely underestimate prevalence.

To counter potential biases from household correlation, the population used for this study excludes PLWD who have a positive screen after their spouse. Therefore, this study may be slightly overestimating spousal caregiving for the larger PLWD population.

2.4.2 *Conclusion*

Our study describes the way PLWD receive care for ADLs and IADLs and is not hypothesis-testing. The impact of this research is limited by the quality of available data and greater investment is needed to provide the data resources necessary to support evidence-based policy. Future longitudinal research using more representative sampling should develop predictive models that inform the relationship between dementia severity and caregiving gaps over time, allowing policy makers to monitor existing caregiving support efforts and pinpoint new opportunities for effective intervention.

Chapter 3. MEDICARE EXPENDITURES AMONG SPOUSES OF PERSONS WITH DEMENTIA

3.1 BACKGROUND

Approximately 1 in 9 adults 65 years and older in the U.S. have a diagnosis of Alzheimer's Disease or Related Dementias as of 2023.[1] Spouses of persons living with dementia (SPWD) are typically adults aged 65 years or older and managing their own health conditions from the often-dwindling household resources shared with their partner.[1,5,20] SPWD typically face increasing care needs for their partner as dementia progresses and higher rates of partner mortality.[1] Eighteen percent of married persons with dementia primarily receive care from their spouse,[14] and nearly half of spousal caregivers are the sole caregiver for their partner.[21]

The stress of caregiving for persons with dementia is well-documented.[1,5] Family members help with household chores, managing functional and cognitive limitations, care coordination, emotional support, and more. As care needs grow over time this can take an increasingly challenging toll on family members' health. Family members of persons with dementia are more likely to be diagnosed with depression and anxiety disorders as well as experience greater and more severe exacerbations of ongoing healthcare conditions relative to similarly aged persons.[1,22–24] There is also immense stress leading up to and following the death of the loved one with dementia, particularly for spouses.[25,26]

Prior studies have shown that people with dementia experience higher healthcare expenditures and use of informal care, in both the initial period after onset, and in the years preceding death.[27,28] The associated financial strains, in addition to providing day-to-day support for a partner with dementia, could translate to different patterns of healthcare use and expenditures for spouses. One hypothesis is that spouses could use more healthcare services due to their greater need, thereby incurring greater expenditures. There is also the possibility that spouses may be too busy, or household financial resources are too strained, to allow them to seek necessary care.[29] Despite the potential impact on spouses of individuals with dementia, few studies have explicitly estimated how this experience impacts healthcare expenditures for spouses.

The existing evidence on how spousal healthcare expenditures relate to a partner's onset of dementia is mixed, with some studies reporting greater relative expenditures among the spouses of individuals with dementia compared with non-dementia dyads, while others show no difference between these groups. Chu et al. (2020)'s cross-sectional study using 2003-2017 Medical Expenditure Panel Survey data[30] and Kolanowski et al. (2004)'s study using private and Medicare Advantage claims found that differences in total healthcare expenditures between SPWD and SPWND were not significant after model adjustment,[31] while Gilden et al. (2017)'s study using the 2001-2005 5% Medicare sample found higher cumulative expenditures ($4,600) for SPWD 31 months from a partner's initial dementia diagnosis relative to a comparison group of SPWND.[32] Suehs et al. (2014)'s longitudinal study of household members of persons living with dementia in a Medicare Advantage program found higher three-year cumulative medical care expenditures ($7,168 vs $6,301 in 2011 dollars) relative to their comparison group without dementia.[29]

The evidence from the existing literature is limited by a reliance on cross sectional data sources, examining populations with prevalent rather than incident dementia,[30,31] and relying on diagnoses from medical care claims as the basis for establishing dementia cases and date of onset. Using cross-sectional data and prevalent populations makes it difficult to determine differences in initial stages of the condition, for example at the subclinical, early, or mild stages, and how utilization changes for an individual over time as their loved one requires more care and support for daily living. Using diagnosis codes can also have limitations in recognizing earlier stages of disease because they are generated by healthcare utilization, and utilization with a dementia diagnosis may not occur until later stages.[33] Diagnosis codes can also miss persons with dementia completely, depending on the timing of coverage and utilization. All these factors can contribute to selecting a sample population whose disease is more severe and costly, leading to overestimation of healthcare expenditures for persons with dementia and their affected family members supporting them.[34]

This study directly estimates traditional Medicare healthcare expenditures among a nationally representative sample of spouses of persons with dementia for 5 years following disease onset. Our study uses data from the Health and Retirement Study (HRS) linked with Medicare claims data to examine the medical expenditures of SPWD over time both before and after disease onset. We matched dyads of spouses and their partners with dementia to comparable dyads of spouses and their partners without dementia on demographic and caregiving characteristics. Monthly expenditures for spouses were then compared five years post dementia onset.

3.2 METHODS

3.2.1 *Data Sources*

This study uses a sample of respondents from the Health and Retirement Study (HRS) with linked Medicare claims. The HRS is a nationally representative longitudinal survey funded by the National Institute on Aging and conducted biennially by the University of Michigan.[17] Individuals aged 50 years and older, along with their spouses, are interviewed to collect comprehensive information regarding socio-demographics, financial resources, health conditions, cognitive function, functional limitations, caregiving, and transitions in living situations. For individuals enrolled in Medicare that provide consent (78%-84%),[35] these data are then linked to deidentified Centers for Medicare and Medicaid Services (CMS) beneficiary and claims data to measure

Medicare expenditures for eligible individuals. The analytic dataset was formed with multiple components including: the 1992-2018 Rand HRS Longitudinal file, the 1995-2018 Langa-Weir Classification of Cognitive Function, and the 1995-2018 HRS core and exit interview data from the Functional Limitations, ADL/IADL, and Helper modules. HRS data were merged using household and person identifiers. These data were then merged to the Medicare beneficiary file to obtain monthly eligibility information and claims to calculate monthly Medicare expenditures.[36]

3.2.2 *Study Sample*

Our study population included spouses whose partner's first positive dementia screen was between 1998-2018 based on the Langa Weir Dementia Classifications: Dementia; Cognitive Impairment, No Dementia (CIND); and No Dementia,[37] with a confirmed negative previous screen and in all follow-up screens.[38] Spouses were limited to those 65 years or older at the time of their partner's dementia onset date to align with Medicare eligibility. Spouses could not have a positive dementia screening before or during their partner's first positive screen, but they could have a positive screen at any subsequent interview.

Spouses must have been enrolled in Medicare Part A and B (also referred to as Traditional or Fee-for-Service Medicare) for 12 months prior to their partner's onset month, the month of onset, and 1 month after. By definition of dementia onset (below), both members of the dyads must have survived at least 1 year past onset. Spouses were then followed-up for up to five years, or until their death, their unenrollment in Parts A & B, or the end of the study period (December 2018).

3.2.3 *Measures*

Dementia status was determined using the Langa Weir Dementia Classifications which are based on cognitive impairment questions during each HRS interview. The dementia onset date was defined as the mid-point between the interview with the first positive dementia screen and the immediately preceding interview, with interviews scheduled at approximately two-year intervals. Matched comparison dyads were assigned the same pseudo-onset date. This assessment and method of onset date assignment is known to be a less biased compared to diagnosis codes in claims because detection relies less on healthcare access and condition severity, which vary by race, income, and education level.[33,34,38]

HRS responses on functional limitations for activities of daily living (ADLs) and instrumental activities of daily living (IADLs)[39] were used to create three categories representing the extent of help that spouses provide for ADLs and IADLs at baseline: 1) no reported ADL/IADL help, 2) help with IADLs only, and 3) help with ADLs, regardless of IADL help. Less than 40 survey respondents in our sample reported they received only help with ADLs.

Monthly Medicare expenditures calculated using claims were aggregated into three cost components: 1) inpatient or hospitalization expenditures, 2) outpatient or ambulatory expenditures including durable medical equipment, and 3) intense daily care covered by Medicare including skilled nursing facility, hospice, and home health. All three categories included supplemented data from carrier (physician) claims files to provide complete information on all charges. All expenditures were inflation-adjusted to 2022 dollars using the Personal Consumption Expenditures price index for healthcare. Prescription claims were not included due to differential enrollment in Part D by spouses of partners with dementia (31%) and with no dementia (38%) in the month of onset.

Sociodemographic and caregiving characteristics used as control variables for matching and modeling were pulled from HRS survey data measured at the first positive screen interview.[36] Spousal chronic conditions used as control variables in modelling were pulled from the CMS chronic condition warehouse if spouses had the condition before their partner's onset date.

3.2.4 *Matching*

SPWD were matched to comparison caregiving spouses based on age (+/- 12 months), sex, race, education level, the wave they entered the HRS, and helper category for their partner's limitations with ADLs and IADLs. SPWND also had to meet the same criteria for inclusion (one year survival, negative dementia screening) based on the pseudo-onset date of the SPWD to which they were matched. SPWD could have a maximum of 5 comparison spouses matched and SPWD without a match were dropped from the analysis. Due to higher mortality for partners with dementia, SPWD dyads were allowed to be controls before their partner's dementia onset, as long as the 5-year follow-up did not overlap in the year prior to onset.[36]

3.2.5 *Statistical Analysis*

Descriptive characteristics of the study sample were summarized to compare SPWD and the first selected controls of the comparison group. After matching, monthly Medicare expenditures were averaged for SPWD and SPWND for total expenditures and each expenditure subtype. A two-part regression model (1st part logistic, 2nd part log-gamma) with standard errors accounting for clustering at individual level was used to model total Medicare expenditures and each category of expenditures separately.[40]

The two-part model included a binary indicator of SPWD vs SPWND, and that binary variable’s interaction with linear month. The regression included fixed quarterly effects, a linear month variable, and controlled for individual level spouse characteristics at baseline including: continuous age, sex, Hispanic ethnicity, education level (less than high school; graduated high school or GED; some college or more), Medicare expenditures in the year before onset quartile categories, private health insurance coverage, and chronic condition indicators for hypothyroidism, cardiovascular disease (heart disease, atrial fibrillation, or heart failure), anemia, respiratory diseases (asthma or chronic obstructive pulmonary disease), eye disorders, renal disease, depression, diabetes, hyperlipidemia, hypertension, osteoporosis, arthritis, stroke, and cancer. Partner and household demographics were also included: partner age, number of ADL and IADL difficulties, and household homeowner status, wealth (non-equity) quartile, and the couple’s number of living children. A categorical variable was included to indicate monthly partner mortality status, partner alive (reference), 12 months prior to partner death, 12 months after partner death, 13-24 months after partner death, and 25 or more months since partner’s death.

We predicted monthly expenditures for SPWD, and their counterfactual expenditures adjusted for the aforementioned covariates, then aggregated them to produce annual cost estimates. Ninety-five percent confidence intervals (CI) for these estimates were calculated by bootstrapping with 5,000 iterations. All analyses were conducted in Stata version 17.0 (StataCorp LLC, College Station, TX).

3.3 RESULTS

3.3.1 *Sample Characteristics*

The matched sample included 516 SPWD dyads and 1,520 SPWND dyads. Table 3.4 summarizes demographic characteristics of SPWD and the first matched SPWND dyad. Shaded rows indicate characteristics used for matching. After matching, SPWND dyads had a slightly higher income, wealth, and rates of homeownership than SPWD dyads. Partners without dementia were, on average, one year younger, and had fewer difficulties with ADLs and IADLs than partners with dementia. SPWND had higher rates of private insurance enrollment, working for pay, and reported less enrollment in Medicaid than their counterparts, though these differences were not statistically significant. SPWND also were more likely to have respiratory diseases (Appendix H). While partners with dementia had a five-year mortality rate twice that of partners without dementia (41.9% vs. 20.1%) there was only slightly greater and statistically insignificant mortality among their spouses over the same period (16.9% vs 16.0%).

Table 3.4. Study population dyad characteristics

Socio-Demographic Characteristics	Spouses of Partners with Dementia		Spouses of Partners with no Dementia, First Match	
Household	n=516		n=516	
*Non-Housing Wealth, median (IQR)	$102,000	($306,200)	$126,500	($396,200)
*Wealth Q1, n (%)	171	(33.1%)	123	(23.8%)
*Wealth Q2, n (%)	107	(20.7%)	137	(26.6%)
*Wealth Q3, n (%)	133	(25.8%)	116	(22.5%)
*Wealth Q4, n (%)	105	(20.3%)	140	(27.1%)
*Homeownership, n (%)	418	(81.0%)	445	(86.2%)
*No Living Children, n (%)	29	(5.6%)	11	(2.1%)
Partner				
*Age, mean (SD)	78.1	(6.5)	76.9	(7.5)
Women, n (%)	224	(43.4%)	224	(43.4%)
Number of Chronic Conditions, median [Q1, Q3]	3	[2, 4]	3	[2, 4]
*Number of Difficult ADLs, median [Q1, Q3]	0	[0, 2]	0	[0, 1]

*Number of Difficult IADLs, median [Q1, Q3]	1	[0, 3]	0	[0, 1]
Spouse				
Age, mean (SD)	77.2	(5.9)	77.2	(5.9)
Women, n (%)	292	(56.6%)	292	(56.6%)
Non-Hispanic White, n (%)	466	(90.3%)	466	(90.3%)
Non-Hispanic Black n (%)	27	(5.2%)	27	(5.2%)
Hispanic, n (%)	22	(4.3%)	22	(4.3%)
Less than High School, n (%)	115	(22.3%)	115	(22.3%)
High School or GED, n (%)	227	(44.0%)	227	(44.0%)
Some College or more, n (%)	174	(33.7%)	174	(33.7%)
No ADL/IADL help, n (%)	289	(56.0%)	289	(56.0%)
Helps with IADLs only, n (%)	108	(20.9%)	108	(20.9%)
Helps with ADLs, n (%)	119	(23.1%)	119	(23.1%)
Private Health Insurance, n (%)	354	(68.6%)	373	(72.3%)
Self-report Medicaid, n (%)	28	(5.4%)	16	(3.1%)
Working, n (%)	57	(11.0%)	70	(13.6%)
Number of Chronic Conditions, median [Q1, Q3]	3	[1, 4]	3	[1, 4]
Medicare Expenditures in Year Prior				
median [Q1, Q3]	$2,344	[$795, $6,725]	$2,339	[$748, $6,475]
Q1, n (%)	127	(24.6%)	125	(24.2%)
Q2, n (%)	142	(27.5%)	145	(28.1%)
Q3, n (%)	122	(23.6%)	126	(24.4%)
Q4, n (%)	125	(24.2%)	120	(23.3%)

*Indicates a significant difference (p-value <0.05). Shaded rows indicate characteristics used to match dyads. IQR-Interquartile range, SD-Standard deviation, Q-Quartile, ADLs-Activities of daily living, IADLs-Instrumental activities of daily living.

3.3.2 *Unadjusted Healthcare Expenditures*

Figure 3.1 depicts average unadjusted monthly Medicare Part A & B expenditures for spouses of partners with and without dementia. In the five-year post onset period, the mean SPWD Medicare expenditures totaled $57,747 compared to $54,135 for SPWND. In the year prior to onset and 1 year post, when both members of the dyads are alive, SPWND had slightly higher expenditures than SPWD, by $817 per person in the year to prior to onset, and $651 in the first post-onset year. In years three, four, and five post-onset this trend switches. In year three, the

SPWD expenditures are higher by $172, and this difference increases to $2,719 and $2,103, in years four and five, respectively.

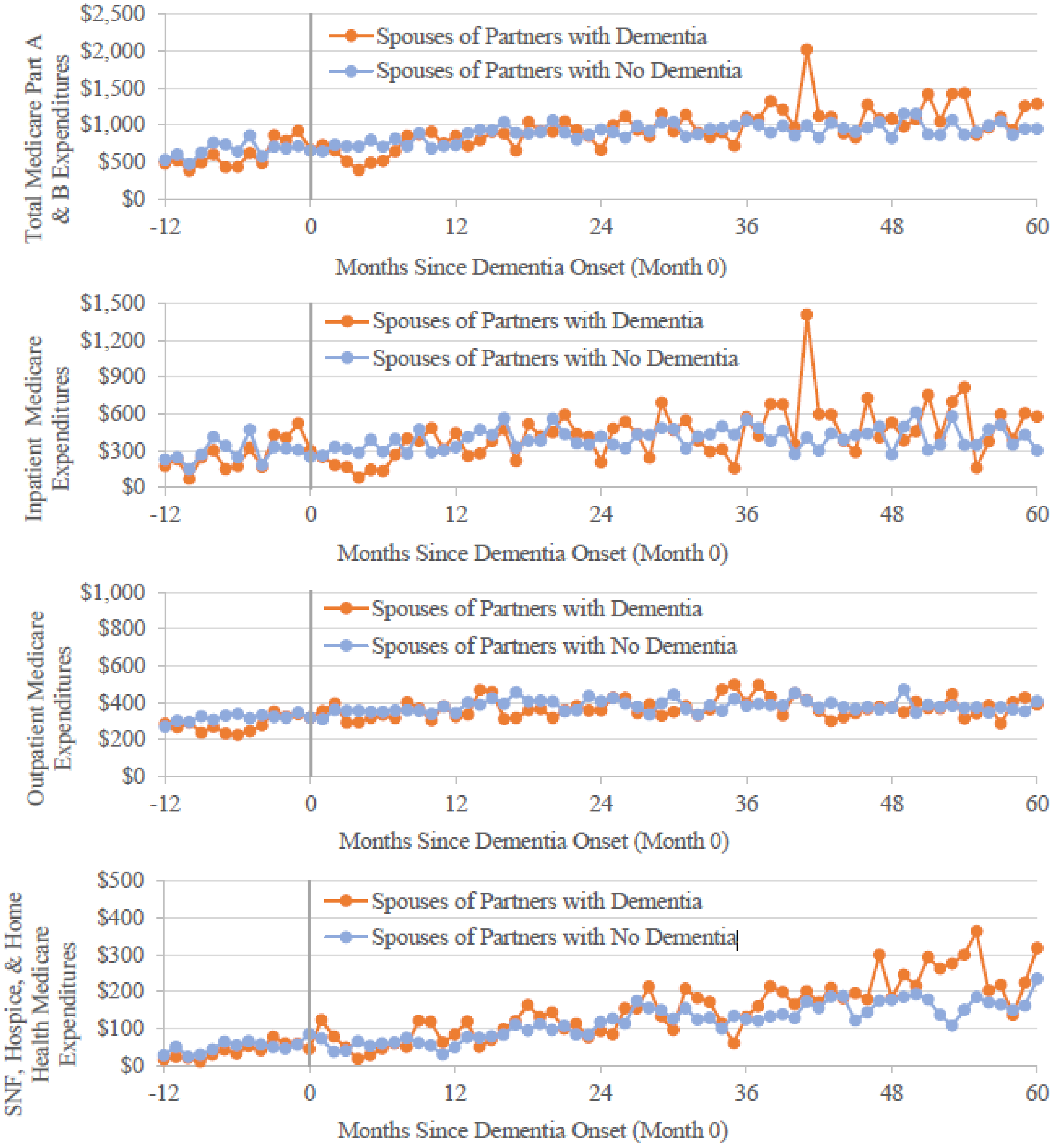


Figure 3.1. Medicare Expenditures in Months since Dementia Onset**Error! Reference source not found.**.

Caption: Figure 1 depicts unadjusted Medicare expenditures by month for spouses of partners with dementia (dark orange) and spouses of partners with no dementia (light blue) in 2022 dollars. The grey reference line refers to the month of dementia onset, month zero. The top panel includes all Medicare Part A and B expenditures, the second includes all inpatient expenditures, the third includes all outpatient or ambulatory expenditures, and the last combines all expenditures for skilled nursing facilities, hospice, and home health services.

3.3.3 *Adjusted Healthcare Expenditures*

Table 3.5 summarizes annual Medicare expenditures after model adjustment for total Part A and B expenditures and by category. Over the five-year post onset period total SPWD Medicare expenditures totaled $60,043 compared to $56,068 for SPWND. This difference, $3,974 (CI = [-$3,199; $11,474]), was not statistically significant. However, there were significant increases in 5-year expenditures for total expenditures ($2,748 [$321; $5,447]), driven by inpatient expenditures ($1,562 [$22; $3,277]). Similar results were found in parsimonious models used as a robustness check for the stability of the full model.

Table 3.5. Adjusted Expenditures Estimates [95% CI], Total Part A & B Medicare and subcategories

Medicare Parts A & B	Spouses of Partners with Dementia		Spouses of Partners with no Dementia		Difference	
Year 1	$7,832	[$6,732, $9,102]	$8,659	[$7,633, $9,856]	-$827	[$-2,149, $458]
Year 2	$10,717	[$9,341, $12,163]	$10,986	[$9,614, $12,443]	-$270	[$-1,651, $1,127]
Year 3	$12,125	[$10,583, $13,937]	$11,519	[$10,107, $13,155]	$606	[$-827, $2,107]
Year 4	$14,356	[$12,440, $16,551]	$12,640	[$11,113, $14,367]	$1,716	[$-174, $3,784]
Year 5	$15,012	[$12,904, $17,692]	$12,265	[$10,783, $14,105]	$2,748	[$321, $5,447]
Total	$60,043	[$54,003, $67,126]	$56,068	[$50,586, $62,319]	$3,974	[$-3,199, $11,477]
Inpatient						
Year 1	$3,289	[$2,593, $4,082]	$3,711	[$3,085, $4,427]	-$422	[$-1,305, $430]
Year 2	$4,782	[$3,961, $5,684]	$4,899	[$4,089, $5,824]	-$117	[$-1,134, $843]
Year 3	$5,107	[$4,186, $6,271]	$4,745	[$3,935, $5,685]	$362	[$-526, $1,345]
Year 4	$6,307	[$5,111, $7,803]	$5,318	[$4,452, $6,315]	$989	[$-199, $2,362]
Year 5	$6,626	[$5,375, $8,237]	$5,065	[$4,209, $6,178]	$1,562	[$22, $3,277]
Total	$26,112	[$22,544, $30,435]	$23,739	[$20,887, $27,112]	$2,373	[$-2,167, $7,387]
Outpatient						
Year 1	$3,797	[$3,311, $4,343]	$3,994	[$3,597, $4,438]	-$197	[$-674, $303]
Year 2	$4,373	[$3,865, $4,902]	$4,563	[$4,076, $5,075]	-$190	[$-648, $286]

Year 3	$4,694	[$4,173, $5,254]	$4,863	[$4,352, $5,400]	-$169	[$-645, $326]
Year 4	$4,851	[$4,290, $5,493]	$4,989	[$4,460, $5,572]	-$138	[$-688, $461]
Year 5	$4,803	[$4,231, $5,493]	$4,906	[$4,368, $5,504]	-$103	[$-781, $645]
Total	$22,518	[$20,267, $25,033]	$23,315	[$21,111, $25,681]	-$797	[$-3,096, $1,603]
SNF, Hospice, & Home Health						
Year 1	$689	[$477, $993]	$833	[$611, $1,147]	-$144	[$-454, $143]
Year 2	$1,248	[$929, $1,664]	$1,394	[$1,026, $1,883]	-$147	[$-581, $247]
Year 3	$1,893	[$1,514, $2,483]	$1,973	[$1,517, $2,636]	-$80	[$-616, $447]
Year 4	$2,541	[$2,058, $3,283]	$2,471	[$1,951, $3,184]	$70	[$-634, $837]
Year 5	$2,966	[$2,312, $3,968]	$2,705	[$2,085, $3,502]	$260	[$-661, $1,357]
Total	$9,337	[$7,881, $11,607]	$9,376	[$7,650, $11,856]	-$40	[$-2,594, $2,605]

SNF-Skilled Nursing Facility

3.4 DISCUSSION

Using HRS and Medicare claims data we estimated total Part A and B expenditures for a sample of spouses of partners with and without dementia enrolled in traditional Medicare and matched on demographic characteristics. We found that cumulative five-year Medicare Part A and B expenditures were not significantly different between SPWD and SPWND, except in the fifth year, when SPWD total expenditures and inpatient expenditures exceeded that of SPWND. This suggests that while Medicare expenditures may not be different for spouses when their partners initially develop dementia, there is an increase in expenditures in later years, particularly for inpatient services (i.e., hospitalizations).

Our study is the first to estimate SPWD healthcare spending for 5 years of follow-up while defining dementia onset using a validated cognitive screening tool rather than diagnosis codes from claims. This may explain differences in our results relative to previous studies,[29,32] as our inclusion criteria likely captures cases at an earlier and therefore less severe disease stage. As a result, the spouses whose experience we analyze may face a lower burden and less strain than other studies using diagnoses from claims to establish disease onset. Accordingly, our results suggest that incremental Medicare expenditures of spouses of partners with dementia are low or negligible in early stages of dementia, but may grow larger as the condition progresses, care needs grow, or the partner dies and spouses' health is impacted.

The spike in total and inpatient expenditures for SPWD in the later years of our study could be related to partner mortality, which is twice as high (41.9% vs. 20.1%) as for SPWND. The stress of supporting a partner near death and dying, could contribute to higher rates of hospitalization.[26,41] There could also be an increase in healthcare utilization after death when the spouse has more time to care for themselves.[10,42]

3.4.1 *Limitations*

After matching, our final sample was slightly older and wealthier than the initial population of SPWD, which reduces the generalizability of our results (see Appendix I for more details). This study only captures traditional Medicare Part A and B expenditures, and this has two consequences: 1) it excludes the growing population of older adults enrolling Medicare Advantage programs and, 2) it captures a limited, though large, portion of the healthcare related expenditures.[1,43] It does not include Medicare prescription drug expenditures, Medicaid expenditures, out-of-pocket expenditures, or private payer/co-insurance expenditures. This study also does not examine long term expenditures differences (beyond 5 years), or changes in healthcare expenditures around partner's transition to a nursing home or death.

Due to data limitations this study does not control for the limited but growing interventions supporting caregivers such as caregiver training, respite care, and new models of wraparound support services such as Medicare's new dementia care model GUIDE.[19] All years of data included (1998-2018) are before the COVID-19 pandemic, which added extra strain onto caregivers and long-term care facilities. Studies using data from 2020-onward may find different results.

3.4.2 *Conclusions*

Despite the differences in caregiving needs, financial burdens, and mortality, we found no significant difference in the 5-years cumulative Part A and B Medicare expenditures for spouses of persons with dementia versus other spouses. This finding could be attributable to using a dementia screening tool to define dementia onset, rather than diagnoses. We likely capture an earlier stage of dementia more consistently for a broader population which may be less straining on spouses. Further research using a similar method should examine patterns of expenditures in later years and around critical timepoints in caregiving, such as partner transitions to formal long-term care settings and death, to better understand healthcare expenditures for spouses of persons living with dementia.

Chapter 4. BEREAVEMENT EFFECTS ON MEDICARE EXPENDITURES FOR SPOUSES OF PERSONS WITH DEMENTIA

4.1 BACKGROUND

One in three adults 65 years and older in the U.S. dies with Alzheimer's disease or related dementia.[1] Of those that are married, nearly 1 in 5 primarily receive care from their spouse, and nearly half are their partner's sole caregiver.[14] Spouses of persons living with dementia (SPWD) often manage their own health conditions while facing increasing care needs as their partner's dementia progresses.[1,5,20,21]

The demands on spouses increase in the months leading up to and following the death of their partner with dementia.[1,5,26,41,44] One study found that in the year prior to a person with dementia's, the majority of family members caring for them felt like they were "on duty" 24 hours a day.[42,45] This strain may translate into different patterns of healthcare seeking behavior among caregivers, including foregoing their own care.[29] Alternatively, SPWD may experience elevated rates of depression and stress, leading to greater healthcare use and high cost acute care events.[1,42]

Previous research has examined the effect of spousal bereavement (spouses surviving their partner's death) on healthcare expenditures[46–49] as well as expenditures of SPWD relative to spouses of persons with no dementia (SPWND),[29–32,50] but to our knowledge, only one paper has studied the impact of spousal bereavement in a population where partners had dementia.[48] Ornstein et al. (2019) used data from the Health and Retirement Study (HRS) to compare Medicare costs in bereaved to non-bereaved dyads in the 24 months post death, and then, in one sub-analysis, examined the bereavement effect for those dying partners with dementia.

We expand on this previous research in two ways. First, our sampling method matched dyads on dementia onset while following couples over 5 years to examine differences in healthcare expenditures among those that experience bereavement, tailoring the analysis to focus on the experiences of SPWD. Second, we explicitly examined differences in expenditures *before* partners death, as well as after death, to determine if the unique conditions of supporting partners with dementia in the year leading up to death result in greater healthcare expenditures for spouses. To test this hypothesis, we used two-part regression models with an interaction between partner dementia status and partner's mortality status to estimate and compare Medicare expenditures in the year leading up to death and the two years after.

4.2 METHODS

4.2.1 *Data Source & Study Sample*

We use data from the HRS, a national longitudinal survey funded by the National Institute on Aging and conducted biennially by the University of Michigan,[17] with linked Medicare claims. We utilized the HRS's feature of surveying spouses, in addition to the initial respondents, to form a matched sample of married couple dyads to compare spouses of persons with dementia to similar spouses of persons with no dementia.[50] The comparison sample was matched on spouse characteristics at their partner's dementia onset, which included age, sex, race, education, and they were reported as a caregiver for their partner. Comparator dyads were assigned a pseudo-onset date of their matched dementia dyad to align periods of 5-year follow-up.

The matched dyad sample included spouses whose partner's first positive dementia screen was between 1998-2018 based on the Langa-Weir Dementia Classification,[37] and onset date was defined as the mid-point between the first positive interview and the immediately previous interview. Spouses were limited to those 65 years or older at the time of their partner's dementia onset date and enrolled in Medicare Part A and B (also referred to as Traditional or Fee-for-Service Medicare) for 12 months prior to their partner's onset month, as well as the month of onset, and 1 month following onset. Spouses were then followed-up for up to five years, or until their death, their disenrollment from Parts A & B, or the end of the study period (December 2018).

Monthly Medicare expenditures were calculated from claims and aggregated into three components: 1) inpatient or hospitalization, 2) outpatient or ambulatory use including durable medical equipment, and 3) intense daily care covered by Medicare including skilled nursing facility (SNF), hospice, and home health. Cost data was adjusted for inflation to 2022 US dollars using the Personal Medical Care Consumer Price Index.

Partner's death was determined through the combination of HRS survey responses linked with the National Death Index, which has high validity with timing of death.[51] In our study, partner mortality status was categorized as partner alive with more than a year left of life (reference category), 12 months prior to partner death (11 months and the month of death), 12 months after partner death, 13-24 months after partner death, and 25 or more months since partner's death.

4.2.2 *Statistical Analysis*

Unadjusted monthly costs for matched spouses of person with and without dementia were examined before and after their partner's death. A two-part regression model (logistic, log-gamma) with standard errors accounting for clustering at the individual level was used to model total as well as component Medicare expenditures.[25] The model uses the complete sample of SPWDs and SPWNDs, regardless of partner's mortality status.

The two-part model includes a binary indicator of SPWD vs SPWND, and the SPWD indicator's interaction with partner's mortality status. In addition to the main effects and key interaction, we controlled for year fixed effects, month (linear) effects, non-time variant covariates. These covariates included individual level spouse characteristics at baseline including: age, sex, Hispanic ethnicity, education level, quartile of Medicare expenditures in the year before dementia onset, private health insurance coverage, and indicators for hypothyroidism, cardiovascular disease, anemia, respiratory diseases, eye disorders, renal disease, depression, diabetes, hyperlipidemia, hypertension, osteoporosis, arthritis, stroke, and cancer. Partner and household demographics were also included: partner age, number of ADL and IADL difficulties, and household homeowner status, wealth quartile, and the number of living children.

Sensitivity analyses were conducted to determine if results were robust to alternative model specifications. Similar two-part and ordinary least squares (OLS) regression models with variables of interest and fixed time effects were run with increasing number of covariates grouped by chronic conditions, spouse characteristics, household and partner characteristics. Different time intervals for partner status were also considered, including a 6-month interval version of partner mortality status, a quarter (3-month) version, and a monthly version.

Monthly expenditures are predicted for SPWD, and adjusted counterfactual expenditures, then aggregated to produce estimates for the year before and two years after their partners died. Ninety-five percent confidence intervals (CI) for these estimates were calculated by bootstrapping with 5,000 iterations. Analyses were conducted in Stata version 17.0 (StataCorp LLC, College Station, TX).

4.3 RESULTS

The matched sample (n=2,036) of SPWD and SPWND had similar characteristics at baseline (Table 3.4).[50] Income, wealth, and rates of homeownership were higher in SPWND and this difference was statistically significant. Survival rates were similar for spouses, but partner's mortality was twice as high for those with dementia compared to partners with no dementia (42% vs 20%).

4.3.1 *Unadjusted Medicare Expenditures*

Figure 4.1 depicts average monthly Medicare Part A and B expenditures for SPWD and SPWND in the months leading up to partner's death (month zero) and in the months after death. Mean spending overlaps in the 24 to 14 months before partner death, but SPWD have higher mean expenditures from 13 months before until 9 months after partner's death (mean difference $470). Inpatient and combined SNF, hospice, and home health expenditures have a similar pattern, while outpatient expenditures mostly overlap between the two groups before and after partner death.

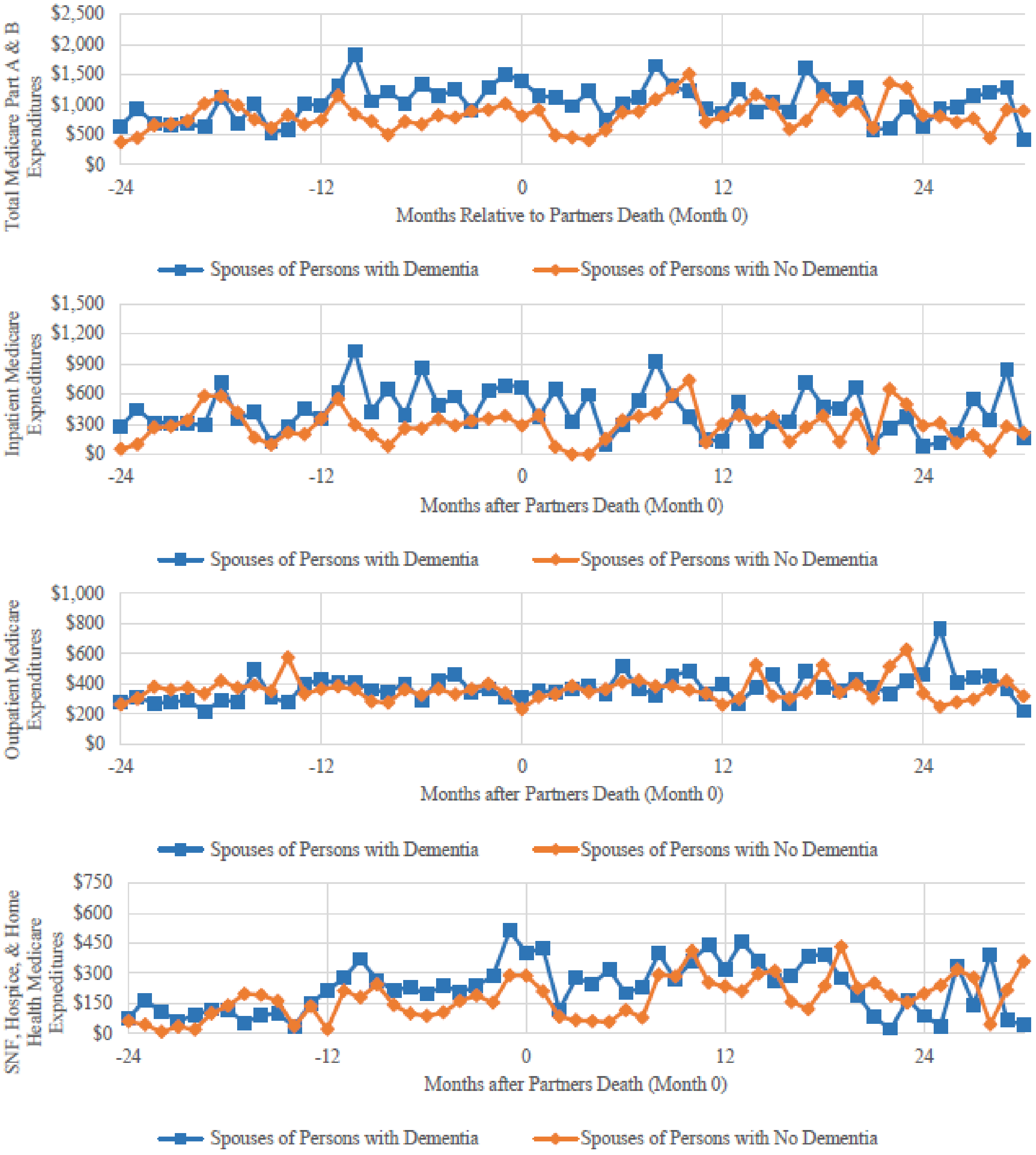


Figure 4.1. Unadjusted Spouse Medicare Expenditures in Months before and after Partners Death **Error! Reference source not found.**.

Caption: Figure 1 depicts unadjusted Medicare expenditures of spouses of partners with dementia (dark blue) and spouses of partners with no dementia (light orange) in 2022 dollars in the months before and after their partner's death.

4.3.2 *Adjusted Medicare Expenditures*

Adjusted 12-month expenditures before and after partner death for total Medicare Expenditures and component costs are reported in Table 4.6. Adjusted expenditures for SWPD in the year prior to their partner's death were significantly (p<0.05) greater than SPWND ($17,372 vs $11,057). In the two years after partner death, SPWD expenditures were lower while SPWND had similar expenditures in the first year after death and then higher expenditures in the second year. Differences between SPWD and SPWND expenditures in each of the two years after death were not statistically significant.

Table 4.6. Adjusted Medicare Expenditures

Total Medicare Part A & B		12 Months Before*	12 Months After	13 to 24 Months After
Spouses of Persons with Dementia	Estimate	$17,372	$14,160	$13,581
	[95% CI]	[$12,813, $22,968]	[$10,733, $18,313]	[$9,965, $17,844]
Spouses of Persons with No Dementia	Estimate	$11,057	$10,573	$12,842
	[95% CI]	[$8,732, $13,653]	[$8,095, $13,480]	[$9,465, $17,086]
Difference	Estimate	$6,315	$3,587	$739
	[95% CI]	[$1,166, $12,289]	[$-552, $8,382]	[$-4,389, $5,943]
Inpatient				
Spouses of Persons with Dementia	Estimate	$7,168	$5,076	$4,644
	[95% CI]	[$4,821, $10,046]	[$3,299, $7,262]	[$2,687, $6,897]
Spouses of Persons with No Dementia	Estimate	$3,845	$3,549	$4,013
	[95% CI]	[$2,606, $5,247]	[$2,246, $5,269]	[$2,403, $6,048]
Difference	Estimate	$3,323	$1,527	$631
	[95% CI]	[$567, $6,397]	[$-864, $4,123]	[$-2,143, $3,297]
Outpatient				
Spouses of Persons with Dementia	Estimate	$4,908	$5,140	$4,967
	[95% CI]	[$4,058, $5,863]	[$4,266, $6,197]	[$3,889, $6,198]
Spouses of Persons with No Dementia	Estimate	$4,548	$5,024	$5,468
	[95% CI]	[$3,765, $5,407]	[$4,087, $6,096]	[$4,076, $7,303]
Difference	Estimate	$360	$116	-$501
	[95% CI]	[$-703, $1,443]	[$-1,105, $1,412]	[$-2,441, $1,243]
Skilled Nursing Facility, Hospice, & Home Health				
Spouses of Persons with Dementia	Estimate	$3,579	$3,553	$3,178
	[95% CI]	[$2,397, $5,203]	[$2,143, $5,366]	[$1,839, $4,815]
Spouses of Persons with No Dementia	Estimate	$2,911	$2,488	$3,501
	[95% CI]	[$1,832, $4,543]	[$1,272, $4,099]	[$1,796, $6,280]
Difference	Estimate	$668	$1,065	-$323

	[95% CI]	[$-1,170, $2,514]	[$-926, $3,203]	[$-3,322, $1,982]

CI-Confidence Interval. Predictions were estimated using a two-part regression model (1st part logistic, 2nd part log-gamma) with standard errors accounting for clustering at individual level for each expenditure type. The model included an interaction between partner dementia status and partner mortality status, and then controlled for spouse age, sex, Hispanic ethnicity, education level, baseline Medicare expenditures, private health insurance coverage, chronic conditions as well as partner age, number of ADL and IADL difficulties, and household homeowner status, wealth, and number of living children.

Differences between SPWD and SPWND across expenditures categories were mostly not significant with the exception of inpatient expenditures. Like total expenditures, there was a significant difference in the first year ($3,323, 95% CI[$567, $6,397]) and no significant differences in the years after.

Estimates and significance were similar across different covariate specifications, and they were similar between OLS and two-part regression versions of the model with all covariates. When examining different time intervals, quarterly and monthly varied by hundreds of dollars from one interval to the next while the 12-month and 6-month version were more stable. The 6-month version did find that expenditures between SPWD and SPWND were significantly different in the first 6 months after partner death, but that effect diminished in the following 6-months.

4.4 DISCUSSION

Overall, we found that SPWD incur an additional $6,315, or 57%, higher Medicare expenditures in the 12 months before their partner's death relative to SPWND. SPWD expenditures are also 55% higher than the average per Medicare beneficiary Part A & B expenditures in 2022.[52] Expenditure patterns are similar between groups *after* partner death; both groups have lower expenditures immediately after partner death with expenditures returning to baseline levels after one year. We find that SPWD incur higher Medicare expenditures in the last year of their partner's life relative to other bereaved spouses. Inpatient expenditures were also significantly higher in the year prior to partner death, therefore SPWD may be experiencing higher rates of hospitalization or more intense hospital stays during this period.

To our knowledge, this is the first paper to examine differences for the impact of bereavement specifically for SPWD compared to similar spouses. Previous studies have shown an association between spousal bereavement and higher mortality and rates of depression, and lower quality of life and greater cognitive decline in dyads aged 65 and older,[47,53–56] and one study showing some effects beginning prior to partner death.[53] No bereavement studies have focused on dementia specifically, though there has been at least one recent study suggesting that having a partner with dementia might have a protective effect on mortality.[57]

Four studies have examined the relationship between spousal bereavement and health care utilization and costs, and those findings were mixed.[46–49] Ornstein et al.[48] matched on bereavement status and then analyzed dyads with dementia. In this subpopulation they found that expenditures among SPWD whose partners died were not significantly higher in the 24-months following death compared to SPWD whose partners survived. However, they did not test for differences between populations with and without dementia or for differences in expenditures prior to death, which limits a direct comparison of our study's finding.

The extant literature reports mixed findings on whether there are differences in healthcare expenditures for SPWD compared to similar SPWND in the years after onset.[29–32,50] In chapter 3, we found that there were not significant differences between SPWD and a similar group of SPWND until the 5th year after dementia onset. However, the simple measure of years after onset may not be capturing differential expenditures related to critical changes in their partner's dementia severity, transitions in housing, and their mortality. This study suggests that one of contributors to differential expenditures between these two groups may be related to partner death, independent of dementia onset.

4.4.1 *Strength & Limitations*

This study utilizes a national data source linked with Medicare claims for adults aged 65 and above and uses a comparable group of spouses matched on key predictors of costs and partners dementia onset time to control for the length of living with a partner with dementia. However, a limited sample size did not support analyses of costs for spouses that die more than 5 years past a spouse's dementia onset, thus our findings may not generalize to spouses with greater post-diagnosis survival.

4.4.2 *Conclusion*

SPWD incurred significantly higher (57%) Medicare expenditures compared to SPWND in the year leading up to partner's death, a significant source of indirect costs associated with dementia for older married couples. Spouses, who are frequently caregivers for their partner with dementia, may need greater support and care as their partner enters end of life care to avoid more intense inpatient expenditures.

Chapter 5. MAJOR FINDINGS & CLOSING THOUGHTS

In Chapter 2, we found that there was a significant increase in the proportion of PLWD that received family care for ADLs and IADLs before and after dementia onset; it nearly doubled. This is not a surprising result considering the needs of PLWD and the qualitative literature examining how caregiving arrangements form, but the finding provides a quantitative answer to the care received by the PLWD population during the transition of dementia onset. We also found that certain subpopulations (Black PLWD, PLWD with lower educational attainment, PLWD with no private health insurance) are less likely to receive help with ADLs or IADLs even after controlling for difficulty with ADLs, IADLs, and co-occurring chronic conditions. This finding provides important information about potential gaps in dementia care, and which subpopulations may benefit most from targeted interventions to enable family care for household members that do not have adequate resources to give care or programs that provide additional formal care.[16]

In Chapters 3 and 4, we examined differences in Medicare expenditures for spouses of PLWD in the first 5 years after onset compared to similar spouses of partners with no dementia. From the simple approach of looking longitudinally, we found no significant differences in the aggregate 5-year expenditures, but there was a significant difference in the last year alone. Spouses of PLWD incurred, on average, $2,748 more Medicare Part A & B expenditures than their counterparts, a 22% increase. When comparing Medicare expenditures around time of partner death, spouses of PLWD incurred significantly higher expenditures ($6,315), than spouses of partners with no dementia in the year leading up to their partners death.

These extra expenditures represent a form of indirect costs of dementia that few studies have quantified before. To date, most indirect costs that have been documented relate to hours of unpaid care and caregivers the loss of income and long-term earning potential.[1,11] Little attention has been paid to spouses, who are frequently retired and no longer working, and healthcare costs of other adult caregivers, whose expenditures can be difficult to capture across the many health insurance providers.[9] At a national level these indirect costs to Medicare are substantial. The single occurrence of partner with dementia death would sum up to $17.7 billion in that year prior to partner death. Longitudinally, accounting for survival for all five years, the additional cost for spouses would sum to nearly $4.5 billion for that fifth year, and if those incremental expenses continue beyond 5 years post onset the indirect costs for spouses could be even higher.[5]

These estimates are specifically for spouses, who are frequently the primary caregiver for married PLWD, and they are facing the mental stress and financial strain of a close relationship with a PLWD. Due to data limitations this study could not quantify similar indirect costs for other family caregivers and household members. If this broader group experiences a similar effect on health that also manifests into higher healthcare expenditures, our study's findings would be an underestimate of the additional indirect costs of dementia related household member and family caregiver impaired health.

In terms of policy implications this body of work contributes, we can look to component expenditures. The differences outlined above were for total Medicare Part A & B expenditures, and significant differences were also found for the inpatient component but were not detected for outpatient or combined skilled nursing facility, home health, and hospice. Higher inpatient expenditures or hospitalization costs could indicate a higher rate of preventable acute events, and that is where caregiver support could provide benefits. There is a growing network of caregiver support systems in the U.S. though access is limited and varies from state to state.[58,59] Continuing to build this infrastructure with the aim of keeping family members and caregivers healthy without adding additional burden could potentially reduce a large component of these indirect costs.

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APPENDIX A

Technical Methods of Chapter 2

Data sources

The HRS is conducted by the University of Michigan and funded by the National Institutes for Aging[17]. It interviews older adults (≥50 years) and their spouses every 2 years, and includes comprehensive information on socio-demographics, financial resources, health conditions, cognitive function, functional limitations, caregiving, and transitions in living situations. The final analytic dataset was formed with multiple components including: the 1992-2018 Rand HRS Longitudinal file[60] the 1995-2018 Langa-Weir Classification of Cognitive Function[18], the 1995-2018 HRS core and exit interview data from the Functional Limitations, ADL/IADL, and Helper modules. Respondents' data were linked and merged using household and person identifiers. In addition to a respondent's first positive screen for dementia, we retained information from the prior interview before and, if available, three interviews after the first positive interview. Due to changes to the survey questions for helpers, this study only utilizes data from 2000 to 2018.

Population of study

Survey participants were included in the sample if they had their first positive dementia screen from 2002-2018 based on the Langa-Wier Classifications[18]. These classifications are based on a cognitive score with a range of 0 to 27. A score between 0 to 6 indicates "Probable Dementia", a score of 7 to 11 indicates "Cognitively Impaired, No Dementia", and score of 12 to 27 indicates "Cognitively Normal". A participant's first positive dementia screening was defined as the first interview where they were classified as having Probable Dementia and they had a prior interview with a non-missing cognitive score and a confirmed classification of either "Cognitively Normal" or "Cognitively Impaired, No Dementia". Participants with a positive dementia screen were excluded if they were less than 50 years old, or if their spouse also had a positive screen for dementia during that interview or during a prior interview.

Previous research[38] has raised the concern that test results of cognitive function may fluctuate, and a single positive finding is insufficient to confirm dementia status. To reduce this concern, the study population was further restricted to those that did not have a screen of Cognitively Normal in the post 3 interviews. However, participants *did remain* in the sample if a post interview screening had a "Cognitively Impaired, No Dementia" screen, or did not have complete data during the post 3 interviews due to death, non-response, or the end of the study period. The final sample included 2,706 HRS participants.

Outcomes

Recording caregiver information in the HRS is conditional on the respondent or their proxy reporting having difficulty with an ADL or IADL and reporting that they receive help for at least 1 ADL or IADL. ADLs include bathing, dressing, walking across the room, getting in and out of bed, and using the toilet; IADLS include using the telephone, taking medications, managing money, shopping for groceries, and preparing hot meals.

The primary outcome for receiving family care was defined as the respondent or their proxy reporting that: 1) they had difficulty with at least one ADL or IADL, 2) they received help for an ADL or IADL, and 3) they report information about at least one helper that was a family member or friend, rather than paid or professional care. Participants could report multiple helpers, and a variety of characteristics for each helper, such as the relationship of the helper and whether they are paid. Indictors of receiving help for each of these activities are described over time in our analyses to inform what kind of activities participants need help with as dementia progresses.

In addition to caregiver relationship and family care receipt, we also examined the number of ADLs and IADLs, and frequency of help with ADLs and IADLs over time. ADLs and IADLs are a common measure that indicate physical and cognitive limitations of a person's ability and are a strong predictor of the need for caregiving, family or formal[61]. If someone is receiving caregiving, it is likely they receive help with a least one of these activities. Indictors of receiving help for each of these activities is described over time in our analyses to inform what kind of activities participants need help with as dementia progresses.

Nursing homes are another setting where PLWD can receive help with ADLs and IADLS, either as a substitute or complement to family care. We therefore also capture information during nursing home stays to comprehensively describe where participants received care. For respondents that died and did not respond to interview request, the exit interview information was used to report on 1) nursing home information 2) receiving help for ADLs and IADLs and 3) caregiving frequency and caregiver attributes.

Other characteristics describing persons living with dementia were pulled directly from the HRS Rand Longitudinal file, including sociodemographic information, working status and income, chronic conditions, functional limitations, and some measures of social resources available.

Statistical Approach

We provide tables summarizing sociodemographic characteristics of PLWD, their utilization of nursing homes facilities, characteristics on the care they received before and after their first positive screen, in addition to figures describing how the number of caregivers changed over time. We also model the probability of receiving family care during the onset interview based on information from previous interview. A logistic regression model was used to predict receiving family care based on sociodemographic characteristics, chronic conditions, and nearness of friends and family including: age, gender, race, ethnicity, education level, marital status, income and wealth quartiles, working status, number of chronic conditions, health insurance type, long term care insurance, life insurance, difficulty with ADLs or IADLS, receiving family care, nursing home status, number of living children, friends nearby (within 10 miles), receiving help with yard work or chores due to a health issue. All data processing and analyses were conducted in StataSE 14 with the margins command used to calculate predicted probabilities[62].

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APPENDIX B

Table of Care Needs and Caregiver Descriptives Pre and Post Dementia Onset

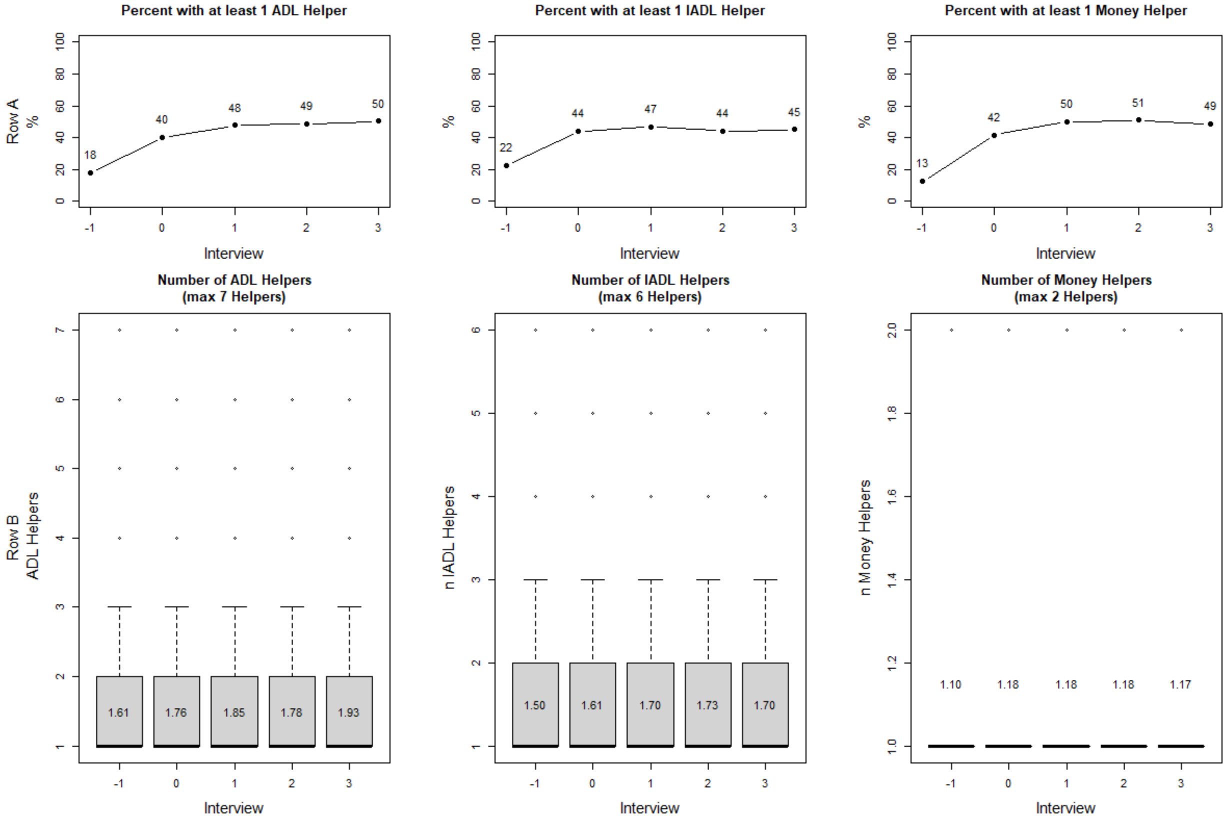
Receipt of Care*	Interview 0 (-2 years) n= 2706		Interview 1 (Onset) n= 2706		Post Interview 1 (+2 years) n = 1762		Post Interview 2 (+4 years) n= 1058		Post Interview 3 (+ 6 years) n= 617	
No Help with ADLs or ADLs, n %	1812	67.0%	1082	40.0%	587	33.3%	359	33.9%	207	33.5%
Any Help with ADL or IADL	894	33.0%	1624	60.0%	1175	66.7%	699	66.1%	410	66.5%
Any Family Care	846	31.3%	1538	56.8%	1112	63.1%	652	61.6%	389	63.0%
ADLs Get Help, n %										
At Least 1 ADL	481	17.8%	1082	40.0%	839	47.6%	516	48.8%	310	50.2%
Bathing	300	11.1%	851	31.4%	562	31.9%	342	32.3%	228	37.0%
Eating	111	4.1%	425	15.7%	286	16.2%	175	16.5%	131	21.2%
Dressing	293	10.8%	802	29.6%	543	30.8%	321	30.3%	208	33.7%
Walking Across the Room	180	6.7%	582	21.5%	366	20.8%	216	20.4%	156	25.3%
In/Out Bed	179	6.6%	541	20.0%	362	20.5%	228	21.6%	152	24.6%
Toilet	104	3.8%	433	16.0%	271	15.4%	191	18.1%	132	21.4%
Count, Get Help for 0 ADL	2225	82.2%	1624	60.0%	1065	60.4%	641	60.6%	349	56.6%
Count, Get Help for 1 ADL	203	7.5%	273	10.1%	143	8.1%	89	8.4%	47	7.6%
Count, Get Help for 2 ADL	98	3.6%	185	6.8%	118	6.7%	60	5.7%	35	5.7%
Count, Get Help for 3 or more ADL	180	6.7%	624	23.1%	436	24.7%	268	25.3%	186	30.1%
IADLs Get Help, n %										
At Least 1 IADL	744	27.5%	1491	55.1%	1089	61.8%	654	61.8%	381	61.8%
Phone	189	7.0%	675	24.9%	516	29.3%	303	28.6%	171	27.7%
Medications	124	4.6%	457	16.9%	352	20.0%	208	19.7%	107	17.3%
Money	339	12.5%	1129	41.7%	878	49.8%	539	50.9%	300	48.6%
Grocery Shopping	401	14.8%	700	25.9%	447	25.4%	248	23.4%	146	23.7%
Preparing Meals	265	9.8%	610	22.5%	399	22.6%	220	20.8%	133	21.6%
Count, Get Help for 0 IADL	1962	72.5%	1215	44.9%	673	38.2%	404	38.2%	236	38.2%
Count, Get Help for 1 IADL	407	15.0%	493	18.2%	384	21.8%	251	23.7%	151	24.5%
Count, Get Help for 2 IADL	184	6.8%	444	16.4%	320	18.2%	190	18.0%	105	17.0%
Count, Get Help for 3 or more I IADL	153	5.7%	554	20.5%	385	21.9%	213	20.1%	125	20.3%
Primary Helper for ADLs Relationship**	n=	481	n=	1082	n=	839	n=	516	n=	310
Spouse, n %	175	36.4%	286	26.4%	160	19.1%	96	18.6%	47	15.2%
Child, n %	116	24.1%	209	19.3%	145	17.3%	84	16.3%	59	19.0%
Other Family/Individual, n %	72	15.0%	104	9.6%	87	10.4%	46	8.9%	32	10.3%
Paid Organization or Professional, n %	118	24.5%	483	44.6%	447	53.3%	290	56.2%	172	55.5%
Primary Helper for IADLs Relationship**	n=	604	n=	1188	n=	827	n=	468	n=	278
Spouse, n %	255	42.2%	448	37.7%	261	31.6%	133	28.4%	76	27.3%
Child, n %	232	38.4%	396	33.3%	275	33.3%	170	36.3%	112	40.3%
Other Family/Individual, n %	84	13.9%	142	12.0%	126	15.2%	58	12.4%	37	13.3%
Paid Organization or Professional, n %	33	5.5%	202	17.0%	165	20.0%	107	22.9%	53	19.1%
Primary Helper for Money Help Relationship**	n=	339	n=	1129	n=	878	n=	539	n=	300
Spouse, n %	106	22.0%	378	34.9%	234	27.9%	139	26.9%	69	22.3%

Child, n %	187	38.9%	589	54.4%	505	60.2%	310	60.1%	186	60.0%
Other Family/Individual, n %	42	15.0%	134	9.6%	103	10.4%	55	8.9%	32	10.3%
Paid Organization or Professional, n %	4	0.8%	28	2.6%	36	4.3%	35	6.8%	13	4.2%

Authors' analysis of data from the Health and Retirement Study, 2002-2018. *Denominator includes participants alive and interviewed, and those that passed and exit information was available. **Denominator included the population if they reported receiving help for that type of activity. ADLs-Activities of Daily Living; IADLs-Instrumental Activities of Daily Living. Participants could report multiple helpers, and a variety of characteristics for each helper, such as the relationship of the helper and whether they are paid.

APPENDIX C

Proportion of PLWD Population Receiving Help (Row A) and Number of Caregivers/Helpers (Row B) for ADLs and IADLs Pre and Post Dementia Onset



Authors' analysis of data from the Health and Retirement Study, 2002-2018. PLWD-Persons Living with Dementia; ADLs-Activities of Daily Living; IADLs-Instrumental Activities of Daily Living. Row A summary statistics presented in the top half include all PLWD with complete survey or exit interview information, even those that did not report difficulties. Row B summary statistics presented in the bottom half only include those that reported at least 1 helper for that activity, whether they be family or formal, paid or not paid. Due to the format of the HRS interview, helper information for money management is reported separately from the rest of the IADLs.

APPENDIX D

Table of Detailed Dementia Population Demographics by Receipt of Family Care at Onset Interview

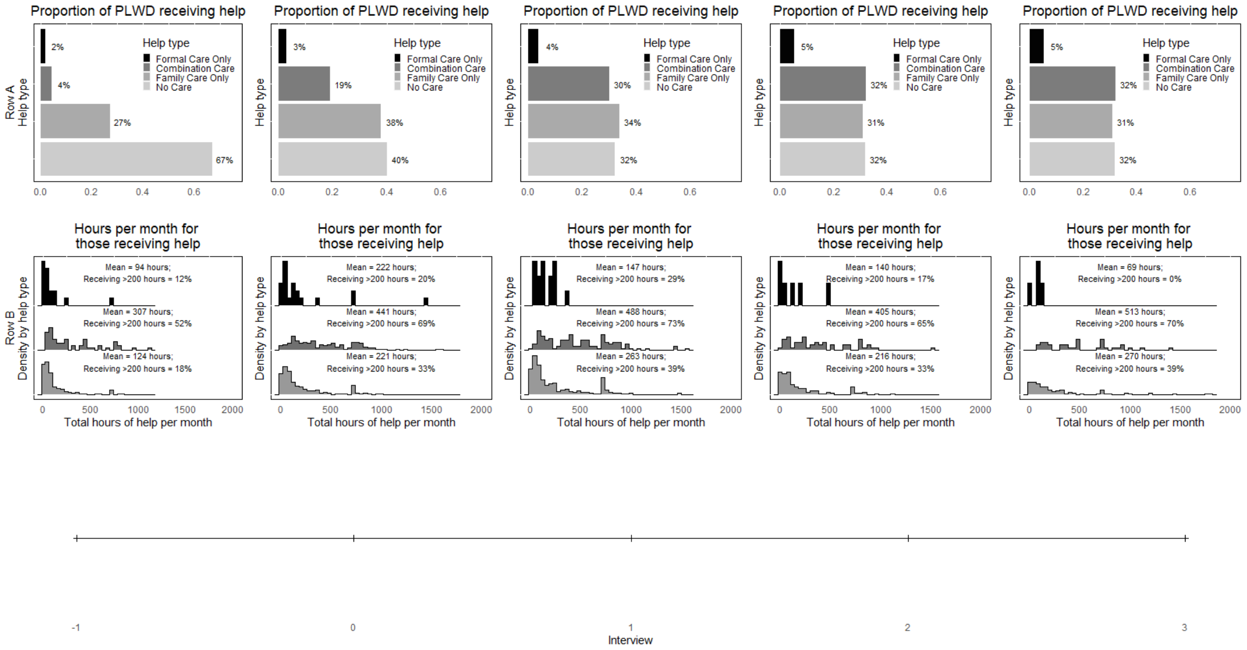
	All PLWD	Not Receiving Family Care	Receiving Family Care	Difference of Group Average
Sociodemographic	n= 2706	n= 1168	n=1538	
Household Income, median [q25, q75]	$20,000 [$11,964, $35,612]	$18,000 [$10,350, $31,994]	$22,071 [$13,098, $38,400]	$4,071
Wealth w/o IRA, median [q25, q75]	$65,000 [$1,500, $232,721]	$50,000 [$875, $188,400]	$76,000 [$2,000, $267,000]	$26,000
No Living Children, n %	202 7.5%	107 9.2%	95 6.2%	-3.0%
One Living Child, n %	303 11.2%	140 12.0%	163 10.6%	-1.4%
Two Living Children, n %	619 22.9%	241 20.6%	378 24.6%	3.9%
Three or More Living Children, n %	1527 56.4%	658 56.3%	869 56.5%	0.2%
Health, Functional Limitations, and Social Resources	n= 2706	n= 1168	n=1538	
High Blood Pressure, n %	1923 71.1%	784 67.1%	1139 74.1%	6.9%
Diabetes, n %	837 30.9%	348 29.8%	489 31.8%	2.0%
Cancer, n %	573 21.2%	196 16.8%	377 24.5%	7.7%
Lung Disease, n %	392 14.5%	131 11.2%	261 17.0%	5.8%
Heart Problems, n %	1056 39.0%	335 28.7%	721 46.9%	18.2%
Stroke, n %	714 26.4%	193 16.5%	521 33.9%	17.4%
Psyche, n %	751 27.8%	224 19.2%	527 34.3%	15.1%
Arthritis, n %	1862 68.8%	704 60.3%	1158 75.3%	15.0%
Cognition Score (0-27)*, mean (SD)	4.8 1.4	5.0 1.3	4.5 1.6	0.4
ADLs Some Difficulty, n %				
At Least 1 ADL	1365 50.4%	222 19.0%	1143 74.3%	55.3%
Bathing	973 36.0%	97 8.3%	876 57.0%	48.7%
Eating	580 21.4%	40 3.4%	540 35.1%	31.7%
Dressing	972 35.9%	120 10.3%	852 55.4%	45.1%
Walking Across the Room	861 31.8%	121 10.4%	740 48.1%	37.8%
In/Out Bed	714 26.4%	94 8.0%	620 40.3%	32.3%
Toilet	630 23.3%	84 7.2%	546 35.5%	28.3%
IADLs Some Difficulty, n %				
At Least 1 IADL	1639 60.6%	165 14.1%	1474 95.8%	81.7%
Phone	910 33.6%	66 5.7%	844 54.9%	49.2%
Medications	802 29.6%	48 4.1%	754 49.0%	44.9%
Money	1209 44.7%	58 5.0%	1151 74.8%	69.9%
Grocery Shopping	1198 44.3%	77 6.6%	1121 72.9%	66.3%
Preparing Meals	1095 40.5%	77 6.6%	1018 66.2%	59.6%
Future Help**, n %	688 25.4%	679 58.1%	9 0.6%	-57.5%

Family Nearby, n %	673 24.9%	241 20.6%	432 28.1%	7.5%
Friends Nearby, n %	1114 41.2%	502 43.0%	612 39.8%	-3.2%
Extra help with yard work/house chores***, n %	986 36.4%	250 21.4%	736 47.9%	26.5%

Authors' analysis of data from the Health and Retirement Study, 2002-2018. *By definition, everyone's score during the first positive interview is below 7. **Suppose in the future, you needed help with basic personal care activities like eating or dressing. Do you have relatives or friends [besides your [husband/wife/partner]] who would be willing and able to help you over a long period of time? ***Receive any help with yard work/house chores (not mentioned in ADL/IADL help) because of a health problem. FC-Family Care; PLWD-Persons Living with Dementia; ADLs-Activities of Daily Living; IADLs-Instrumental Activities of Daily Living; SD-Standard Deviation.

APPENDIX E

Type of Help Received (Row A) and Number of Hours per Month of Help Received (Row B) for ADLs and IADLs Pre and Post Dementia Onset



Authors’ analysis of data from the Health and Retirement Study, 2002-2018. PLWD-Persons Living with Dementia. Summary statistics presented in the top half include all PLWD with complete survey or exit interview information, even those that did not report difficulties. Summary statistics presented in the bottom half only include those that reported at least 1 helper and had complete hourly data on all the helpers they reported.

APPENDIX F

Table of Mortality and Nursing Home Utilization Pre and Post Dementia Onset

Interview Status, Mortality, n % cohort	Interview 0 (-2 years)		Interview 1 (Onset)		Post Interview 1 (+ 2 years)		Post Interview 2 (+4 years)		Post Interview 3 (+ 6 years)	
	n=	2706	n=	2706	n=	2706	n=	2706	n=	2706
Alive and Responded, alive by end of wave	2706	100.0%	2247	83.0%	1262	46.6%	753	27.8%	453	16.7%
Alive and Responded, but died by end of wave	0	100.0%	459	17.0%	270	10.0%	126	4.7%	73	2.7%
No Response and death during interview wave, exit interview information is used if available	0	0.0%	0	0.0%	230	8.5%	179	6.6%	91	3.4%
No Response, died in previous wave	0	0.0%	0	0.0%	459	17.0%	957	35.4%	1262	46.6%
Alive but no response this wave	0	0.0%	0	0.0%	196	7.2%	151	5.6%	103	3.8%
Self-selected out of study, this wave or prior	0	0.0%	0	0.0%	0	0.0%	14	0.5%	18	0.7%
No Response, End of Study Period	0	0.0%	0	0.0%	289	10.7%	526	19.4%	706	26.1%
Cohort Mortality, n %	0	0.0%	0	0.0%	959	35.4%	1262	46.6%	1426	52.7%
Surviving Population with NH Utilization data	n=	2706	n=	2683	n=	1709	n=	999	n=	580
Any Time in a NH Since Last Interview, n %	264	9.8%	704	26.2%	569	33.3%	349	34.9%	210	36.2%
Currently in a NH as of Interview/at Death, n %	106	3.9%	475	17.7%	437	25.6%	293	29.3%	167	28.8%
Number of Stays in NH since last interview*, n%										
1 Stay	211	79.9%	511	72.6%	446	78.4%	255	73.1%	161	76.7%
2 Stays	30	11.4%	92	13.1%	56	9.8%	48	13.8%	16	7.6%
3 or More Stays	12	4.5%	51	7.2%	28	4.9%	20	5.7%	10	4.8%
Missing	11	4.2%	50	7.1%	39	6.9%	26	7.4%	23	11.0%
Number of Nights in NH since last interview*, n%										
0-90 Nights	144	54.5%	296	42.0%	174	30.6%	76	21.8%	48	22.9%
91-180 Nights	26	9.8%	66	9.4%	31	5.4%	20	5.7%	11	5.2%
181-365 Nights	24	9.1%	73	10.4%	48	8.4%	40	11.5%	14	6.7%
>365 Nights	50	18.9%	218	31.0%	275	48.3%	183	52.4%	118	56.2%
Missing	20	7.6%	51	7.2%	41	7.2%	30	8.6%	19	9.0%

Authors' analysis of data from the Health and Retirement Study, 2002-2018. *Conditional on any time in a nursing home. NH-Nursing Home. Summary statistics presented include all Persons Living with Dementia with complete survey or exit interview information, even those that did not report difficulties.

APPENDIX G

Table of Regression Output Odds Ratios of Receiving Family Care at Onset Interview

Variable	Odds Ratio	Standard Error	p-value	95% Confidence Interval	
Age, years	1.030	0.006	0.000	1.019	1.041

Women, reference Men	0.870	0.086	0.158	0.717	1.056
Married, reference Not Married	1.245	0.144	0.059	0.992	1.561
Race White/Caucasian, reference Black/African American	1.453	0.179	0.002	1.141	1.851
Race Other, reference Black/African American	1.253	0.265	0.286	0.828	1.898
Hispanic, reference Non-Hispanic	0.948	0.145	0.727	0.702	1.280
GED or High School, reference Less than High School	1.288	0.141	0.021	1.039	1.597
Some College or More, reference Less than High School	1.550	0.191	0.000	1.217	1.974
Working for Pay, reference Not Working for Pay	0.751	0.118	0.068	0.553	1.022
2nd Income quartile, reference 1st (Lowest)	0.784	0.112	0.088	0.593	1.037
3rd Income quartile, reference 1st (Lowest)	1.003	0.151	0.983	0.746	1.349
4th Income quartile, reference 1st (Lowest)	0.949	0.158	0.751	0.685	1.314
5th Income quartile, reference 1st (Lowest)	1.107	0.202	0.576	0.774	1.583
2nd Wealth quartile, reference 1st (Lowest)	0.854	0.126	0.284	0.640	1.140
3rd Wealth quartile, reference 1st (Lowest)	1.002	0.154	0.990	0.741	1.354
4th Wealth quartile, reference 1st (Lowest)	0.911	0.150	0.569	0.660	1.257
5th Wealth quartile, reference 1st (Lowest)	0.976	0.175	0.892	0.686	1.388
Extra Chronic Condition	1.149	0.037	0.000	1.079	1.223
Medicare	1.080	0.164	0.611	0.802	1.456
Medicaid	1.037	0.148	0.798	0.784	1.372
Private Health Insurance	1.255	0.122	0.019	1.038	1.519
Long Term Care HI	1.212	0.193	0.228	0.887	1.656
Life Insurance	0.983	0.090	0.856	0.821	1.178
Extra IADL Limitation	1.406	0.106	0.000	1.213	1.629
Extra ADL Limitation	1.073	0.058	0.194	0.965	1.193
Any Nursing Home Visits previous 2 years	0.997	0.173	0.985	0.709	1.402
One Living Child, reference none	1.063	0.210	0.757	0.722	1.565
Two Living Children, reference none	1.293	0.225	0.139	0.920	1.819
Three or more Living Children, reference none	1.274	0.202	0.127	0.934	1.740
Living Near Friends	1.174	0.106	0.075	0.984	1.401
Currently Receiving Family Care	2.651	0.396	0.000	1.978	3.554
Help with chores/yardwork*	1.496	0.151	0.000	1.227	1.823
Constant	0.023	0.010	0.000	0.010	0.054

Authors' analysis of data from the Health and Retirement Study, 2002-2018.*Receive any help with yard work/house chores (not mentioned in ADL/IADL help) because of a health problem. N = 2,706; Pseudo R2 = 0.173. Highlighted rows indicate variables with significant effects (p-value < 0.05).

APPENDIX H

Table of spousal caregiver chronic conditions

Condition	Spouses of Partners with Dementia n=516		Spouses of Partners with no Dementia, First Match n=516	
Hypothyroidism	62	(12.0%)	50	(9.7%)
Heart Disease	157	(30.4%)	186	(36.0%)
Anemia	93	(18.0%)	80	(15.5%)
Respiratory Disease*	61	(11.8%)	34	(6.6%)
Atrial Fib	31	(6.0%)	40	(7.8%)
Eye Disorder	197	(38.2%)	207	(40.1%)
Renal Disease	38	(7.4%)	39	(7.6%)
Depression	38	(7.4%)	27	(5.2%)
Diabetes	118	(22.9%)	118	(22.9%)
Heart Failure	65	(12.6%)	60	(11.6%)
Hyperlipidemia	185	(35.9%)	209	(40.5%)
Hypertension	266	(51.6%)	258	(50.0%)
Osteoporosis	28	(5.4%)	25	(4.8%)
Arthritis	130	(25.2%)	130	(25.2%)
Stroke	14	(2.7%)	12	(2.3%)
Cancer	55	(10.7%)	50	(9.7%)

*Indicate a significant difference (p-value <0.05).

APPENDIX I

Table of spouses of partners with dementia dyad characteristics, pre and post matching

Socio-Demographic Characteristics	Pre-Match n=802		Post-Match n=516	
Household				
Income, median (IQR)	$30,787	($30,217)	$32,271	($29,996)
Non-Housing Wealth, median (IQR)	$76,000	($290,000)	$102,000	($306,200)
Homeownership	629	(78.4%)	418	(81.0%)
No living Children, n (%)	36	(4.5%)	29	(5.6%)
Partner				
Age, mean (SD)	78.6	(7.0)	78.1	(6.5)
Women, n (%)	346	(43.1%)	224	(43.4%)
Number of Chronic Conditions, median [Q1, Q3]	3	[2, 4]	3	[2, 4]
Number of Difficult ADLs, median [Q1, Q3]	0	[0, 3]	0	[0, 2]
Number of Difficult IADLs, median [Q1, Q3]	1	[1, 4]	1	[0, 3]
Spouse				
Age, mean (SD)	77.6	(6.4)	77.2	(5.9)
Women, n (%)	456	(56.9%)	292	(56.6%)

Non-Hispanic White, n (%)	642	(80.0%)	466	(90.3%)
Non-Hispanic Black n (%)	77	(9.6%)	27	(5.2%)
Hispanic, n (%)	72	(9.0%)	22	(4.3%)
Less than High School, n (%)	239	(29.8%)	115	(22.3%)
High School or GED, n (%)	305	(38.0%)	227	(44.0%)
Some College or more, n (%)	258	(32.2%)	174	(33.7%)
No ADL/IADL help	360	(44.9%)	289	(56.0%)
Helps with IADLs only	218	(27.2%)	108	(20.9%)
Helps with ADLs	224	(27.9%)	119	(23.1%)
Private Health Insurance, n (%)	515	(64.2%)	354	(68.6%)
Self-report Medicaid, n (%)	70	(8.7%)	28	(5.4%)
Working, n (%)	78	(9.7%)	57	(11.0%)

Shaded rows indicate characteristics used to match dyads. IQR-Interquartile range, SD-Standard deviation, Q1-First quartile or 25th percentile, Q3-Third quartile or 75th percentile, ADLs-Activities of daily living, IADLs-Instrumental activities of daily living.

VITA

[A short bio of the author is required for a Ph.D. dissertation at the University of Washington. The vita section does not go into the Table of Contents. The formatting style follows the text of the dissertation.]