



Residential Setting and the Cumulative Financial Burden of Dementia in the 7 Years Before Death

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OBJECTIVES: Care for older adults with dementia during the final years of life is costly, and families shoulder much of this burden. We aimed to assess the financial burden of care for those with and without dementia, and to explore differences across residential settings.

DESIGN: Using the Health and Retirement Study (HRS) and linked claims, we examined total healthcare spending and proportion by payer—Medicare, Medicaid, out-of-pocket, and calculated costs of informal caregiving—over the last 7 years of life, comparing those with and without dementia and stratifying by residential setting.

SETTING: The HRS is a nationally representative longitudinal study of older adults in the United States.

PARTICIPANTS: We sampled HRS decedents from 2004 to 2015. To ensure complete data, we limited the sample to those 72 years or older at death who had continuous fee-for-service Medicare Parts A and B coverage during the 7-year period (n = 2909).

MEASUREMENTS: We compared decedents with dementia at last HRS assessment with those without dementia across annual and cumulative 7-year spending measures, and personal characteristics. We present annual and cumulative spending by payer, and the changing proportion of spending by payer over time, comparing those with and without dementia and stratifying results by residential setting.

RESULTS: We found that, consistent with prior studies, people with dementia experience significantly higher costs, with a disproportionate share falling on patients and families. This pattern is most striking among community residents with dementia, whose families shoulder 64% of total expenditures (including \$176,180 informal caregiving costs and \$55,550 out-of-pocket costs), compared with 43% for people with dementia residing in nursing homes (\$60,320 informal caregiving costs and \$105,590 out-of-pocket costs).

CONCLUSION: These findings demonstrate disparities in financial burden shouldered by families of those with dementia, particularly among those residing in the community. They highlight the importance of considering the residential setting in research, programs, and policies. *J Am Geriatr Soc* 00:1-6, 2020.

Keywords: dementia; Medicare and Medicaid; health-related costs; nursing home; community-dwelling older adults

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Healthcare costs among persons with dementia are strikingly high in the last years of life, particularly in comparison with those dying of heart disease, cancer, or other causes.^{1,2} These high costs persist for years over the slowly debilitating course of illness. For the families of those with dementia, the burden of out-of-pocket spending and costs related to informal caregiving may represent a particular strain on resources.²⁻⁹ As more older adults forgo or are unable to access institutional care settings and thus remain in the community, the burden on families may be increasing. Yet to date, little is known about the longitudinal patterns of out-of-pocket spending, additional costs related to informal caregiving, or how these costs may vary by residential setting (ie, community vs nursing home).

In addition to the financial burden borne by families, governments, and thus taxpayers, face sizable costs as well.

Medicaid is the largest payer for long-term services and supports, both in nursing homes and community settings.¹⁰ Thus both state and federal governments will face substantial increases in Medicaid costs as the population with dementia increases. A wide range of policies are being considered to address both public and private spending as well as the burden placed on informal caregivers; however, the data needed to inform these policies are limited.¹¹

In previous work, we considered total Medicare, out-of-pocket, and implicit informal caregiving costs of dementia in the last 5 years of life. However, our analysis did not consider residential setting. It also was limited to imputed Medicaid costs, and it did not consider the temporal pattern of enrollment in Medicaid among those with dementia relative to those without. We are not aware of any other research that has examined this full range of healthcare costs across payers and considered residential status over time.

In this study, we examine total healthcare spending and proportion by payer over the last 7 years of life using the nationally representative Health and Retirement Study (HRS). We use data on health-related out-of-pocket spending, costs of informal care, and household net wealth, linked to individuals' Medicare and Medicaid claims data, to compare costs for those with dementia and those without. We then examine these costs stratified by residential setting (ie, nursing home vs community).

METHODS

Data and Study Population

The HRS is a national longitudinal study of adults older than 50 years of age in the United States.¹² Biennial interviews collect detailed data including demographic, functional, and medical characteristics; household spending and financial information; and caregiving needs and hours of support. HRS survey data can be linked to individual Medicare and Medicaid data.

We sampled all HRS decedents aged 72 years or older at death from 2004 to 2015 and combined each decedent's survey data with Medicare and Medicaid claims from the 7 years before death. To avoid missing data, the sample was limited to those who had continuous fee-for-service Medicare Parts A and B coverage during the 7 years preceding death. Those excluded due to incomplete fee-for-service Medicare coverage ($n = 2785$) were on average 1 year younger and more likely to be black or Hispanic, have lower net worth and educational attainment, and more likely to be dually eligible for Medicaid (Supplementary Table S1). The final sample included 2909 decedents.

Seven-Year Study Period

Our prior research describing healthcare spending in the last 5 years of life demonstrated that differences between those with dementia and those without are already established 5 years before death.² Therefore, we selected a longer study period to capture spending patterns before onset of dementia or earlier in the course of the disease. Although a 7-year period was feasible, extending the study beyond 7 years, and thus restricting the sample to those with a longer period of complete data, including healthcare claims, would decrease

the size of the study sample leading to less generalizable results.

Dementia Group

We assigned participants to the dementia group if the probability of dementia at the last available HRS assessment, on average 12 months before death, was greater than 50%. The remaining participants were assigned to the comparison group. Probability of dementia was assessed using a clinically validated algorithm based on responses to a battery of cognitive and functional measures and demographic data.^{1,13,14} This approach to identifying participants with dementia is commonly used in studies of the HRS cohort.^{1,2,4}

Expenditure Measures

Medicare expenditures were summed across all inpatient, outpatient, skilled nursing facility, hospice, home health, and durable medical equipment claims for each of the 7 years before death. Medicaid expenditures were also summed for each year before death. Annual costs for Medicaid enrollees for whom linked data were not available (7% of participants) were imputed based on HRS and Medicare data. We conducted sensitivity analyses excluding those with missing Medicaid data and found no significant changes in results. Health-related out-of-pocket spending was reported in each HRS interview and included insurance, hospital, physician, medication, and nursing home costs; hired helpers; in-home medical care; and other expenses.^{2,15-17} To estimate the cost of caregiving provided by unpaid helpers, we summed the participants' reported hours of informal care, capped at 720 hours per month for help from all sources; we then multiplied this by the state's median costs of a home health aide.¹⁸ The cost of nursing home nights remaining after accounting for nights covered by Medicare or Medicaid, or paid for out-of-pocket, were attributed to "other" payers for participants who reported coverage through either the Veterans Health Administration (VA) or private long-term care insurance (for those without VA benefits). For all spending categories, we prorated expenditures to each measurement year as needed and adjusted for inflation to 2016 US dollars based on the Consumer Price Index.

Residential Setting and Participant Characteristics

We assessed residential setting and other participant characteristics at baseline (on average, 7 years before death) and at the last HRS interview (on average, 1 year before death). All non-nursing home residences were categorized as community settings. Chronic medical conditions were measured using Medicare claims data, and Medicaid enrollment was determined by the Medicaid state buy-in indicator in the Medicare Summary Beneficiary File.

Analyses

We tested the differences between decedents with and without dementia across all annual and total (7-year) spending measures using Wilcoxon rank sum due to the skewed nature of expenditures, and across baseline and final characteristics using t tests for continuous variables and χ^2 tests

Table 1. Characteristics at Baseline and Last Year of Life, by Dementia Status

	Full sample	No dementia	Dementia	P value ^a
<i>N</i>	2909	1715	1194	
Female	57.00	51.31	65.16	<.01
Race/Ethnicity				
Hispanic	4.50	3.44	6.03	<.01 ^b
Non-Hispanic black	11.52	8.92	15.24	
Non-Hispanic white/other	83.98	87.64	78.73	
Education, high school graduate	67.82	74.64	58.04	<.01
Baseline, on average 7 y before death				
Age	77.92	75.59	81.28	<.01
Proxy respondent	10.62	4.49	19.43	<.01
Married	50.64	56.97	41.54	<.01
ADL dependent	13.10	7.29	21.44	<.01
Self-rated health: poor/fair	39.14	36.19	43.37	<.01
≥4 chronic conditions ^c	50.74	49.39	52.68	.08
Medicaid, enrolled ^d	14.51	10.20	20.69	<.01
VA insurance coverage	6.39	7.29	5.11	.02
Private Medigap insurance coverage	48.09	51.37	43.38	<.01
LTC insurance coverage	11.76	13.35	9.46	<.01
Nursing home resident	3.54	.76	7.54	<.01
Net worth, mean ^e	\$567,622	\$646,599	\$454,185	<.01
Last year of life, on average 1 y before death				
Age ^f	84.92	82.59	88.27	<.01
Proxy respondent	29.12	6.71	61.47	<.01
Married	38.12	45.19	27.97	<.01
ADL dependent	45.00	24.61	74.29	<.01
Self-rated health: poor/fair	59.64	55.16	66.08	<.01
≥4 chronic conditions ^c	89.14	90.90	86.60	<.01
Medicaid, enrolled ^d	19.59	13.00	29.06	<.01
VA insurance coverage	7.29	8.07	6.16	.05
Private Medigap insurance coverage	59.42	64.31	52.23	<.01
LTC insurance coverage	10.28	11.49	8.54	.01
Nursing home resident	21.76	6.65	43.47	<.01
Years in NH before death among residents, mean	3.48	3.05	3.57	.06
Net worth, mean ^e	\$446,448	\$514,988	\$348,001	<.01
Median	\$137,986	\$192,042	\$65,303	
Total health-related spending over last 7 y of life, by payer				
Total spending over last 7 y, mean	\$296,233	\$243,311	\$372,248	<.01
Median	\$241,972	\$197,872	\$320,055	
90th percentile	\$560,350	\$457,766	\$681,112	
Medicare expenditures, mean	\$124,418	\$129,132	\$117,647	<.01
Median	\$99,302	\$102,715	\$94,269	
Medicaid expenditures, mean	\$23,027	\$9,288	\$42,766	<.01
Median	\$0	\$0	\$0	
Imputed cost of informal care, mean	\$79,667	\$47,538	\$125,815	<.01
Median	\$20,290	\$10,218	\$43,169	
Out-of-pocket, mean	\$64,400	\$55,417	\$77,302	<.01
Median	\$51,549	\$50,331	\$56,203	
Total cost to family (informal care and out-of-pocket)	\$144,067	\$102,955	\$203,117	<.01
Nursing home costs attributed to LTC or VA coverage, mean	\$4722	\$1940	\$8718	<.01
Median	\$0.00	\$0.00	\$0.00	

Abbreviations: ADL, activity of daily living; LTC, long-term care; VA, Veterans Health Administration.

^aP values compare dementia with no dementia.

^bP value is for three-way comparison; two-way comparison of white to nonwhite, $P < .01$.

^cFrom *International Classification of Diseases (ICD)-9* and ICD-10 diagnosis codes algorithms from the Chronic Conditions Warehouse, out of 26 condition categories, excluding Alzheimer's dementia.

^dFrom State Buy-in in the Medicare Beneficiary Summary File.

^eInflation adjusted to 2016 dollars using the CPI-U.

^fAge at death.

for categorical variables. We present annual and cumulative health-related spending by payer and the changing proportion of spending by payer over time, comparing those with dementia with those without and stratifying results by residential setting. We also conducted sensitivity analyses with adjustment of the results, consistent with prior work,² and found similar results.

RESULTS

Those with dementia were more likely to be older, female, and unmarried; belong to a racial or ethnic minority group; and report poor health and function (Table 1). During the study period, median net wealth decreased 58% among those with dementia and 34% among those without. Enrollment in Medicaid increased from 21% to 29% among those with dementia, compared with an increase from 10% to 13% among those without dementia. Total mean spending over the last 7 years of life among those with dementia was more than 50% higher than among those without dementia, \$372,250 and \$243,310, respectively. The distribution of spending was highly skewed, with the 90th percentile of total spending

equal to \$681,112 for people with dementia and \$457,766 for those without dementia. Medicaid spending among those with dementia was much higher than for those without dementia (\$42,770 compared with \$9280), and Medicare spending was slightly lower (\$117,647 vs \$129,132). Through out-of-pocket spending and costs of informal caregiving, families of persons with dementia contributed \$203,110 while other families contributed \$102,960, on average.

Among participants with dementia, total costs for those residing in nursing homes before death (\$382,350) were similar to costs for those residing in community settings before death (\$364,480). However, for participants with dementia in community settings, a greater proportion of these costs were attributed to informal caregiving and out-of-pocket expenditures, compared with participants with dementia in nursing homes. These two categories combined represented 64% of total expenditures for community-dwelling people with dementia (\$176,180 in informal caregiving costs and \$55,550 in out-of-pocket costs), compared with 43% for people with dementia residing in nursing homes (\$60,320 in informal caregiving costs and \$105,590 in out-of-pocket costs). In contrast, among those without

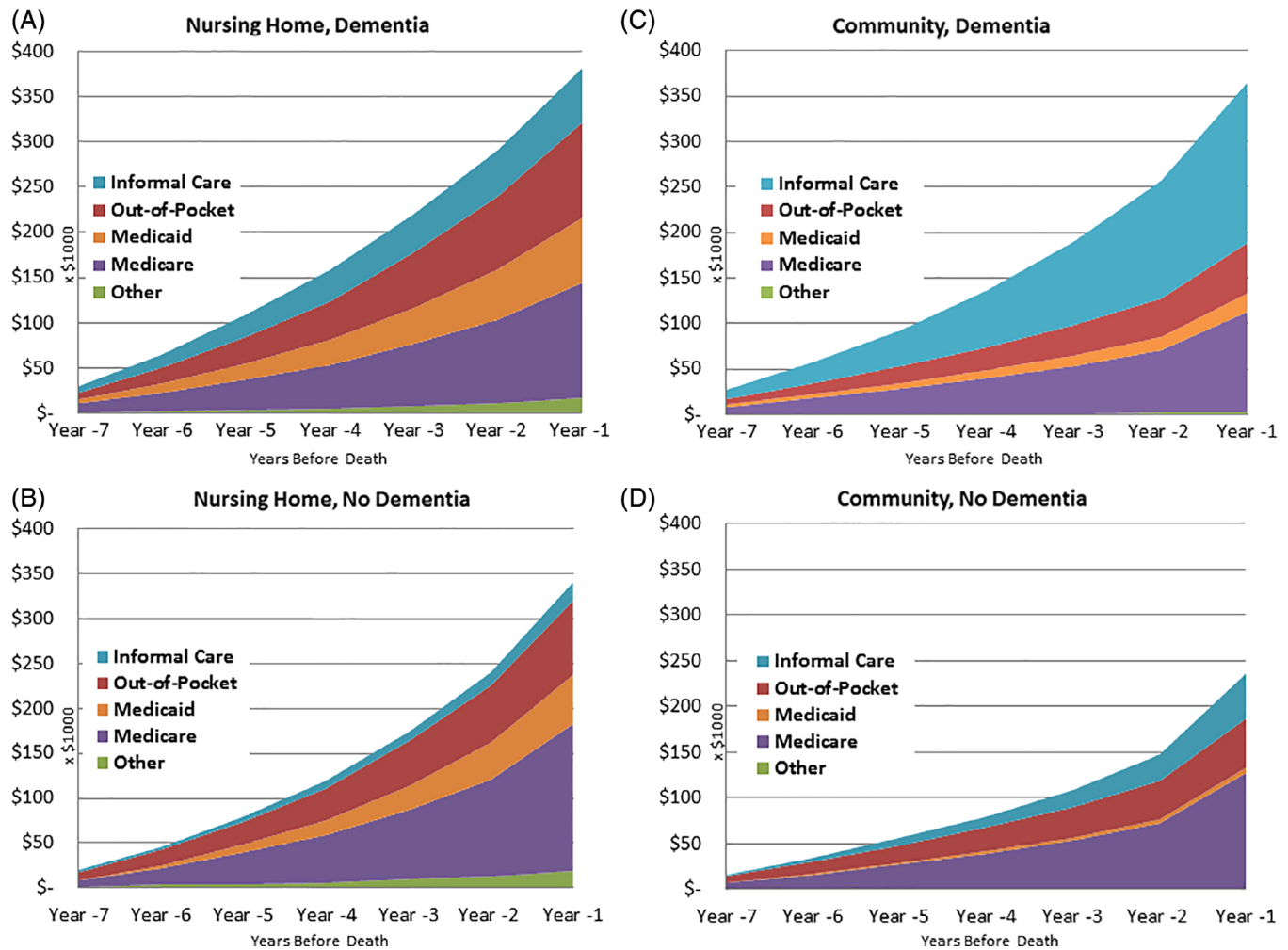


Figure 1. Cumulative mean spending over last 7 years of life among nursing home and community residents, by dementia status ($\times \$1000$). Authors' analysis of data from the Health and Retirement Study, linked to Medicare and Medicaid claims data. Residential status based on survey in the year before death. The figure depicts mean values ($\times \$1000$); median values are presented in Table 1. (A) Nursing home, dementia ($n = 519$); (B) nursing home, no dementia ($n = 114$); (C) community, dementia ($n = 675$); (D) community, no dementia ($n = 1601$).

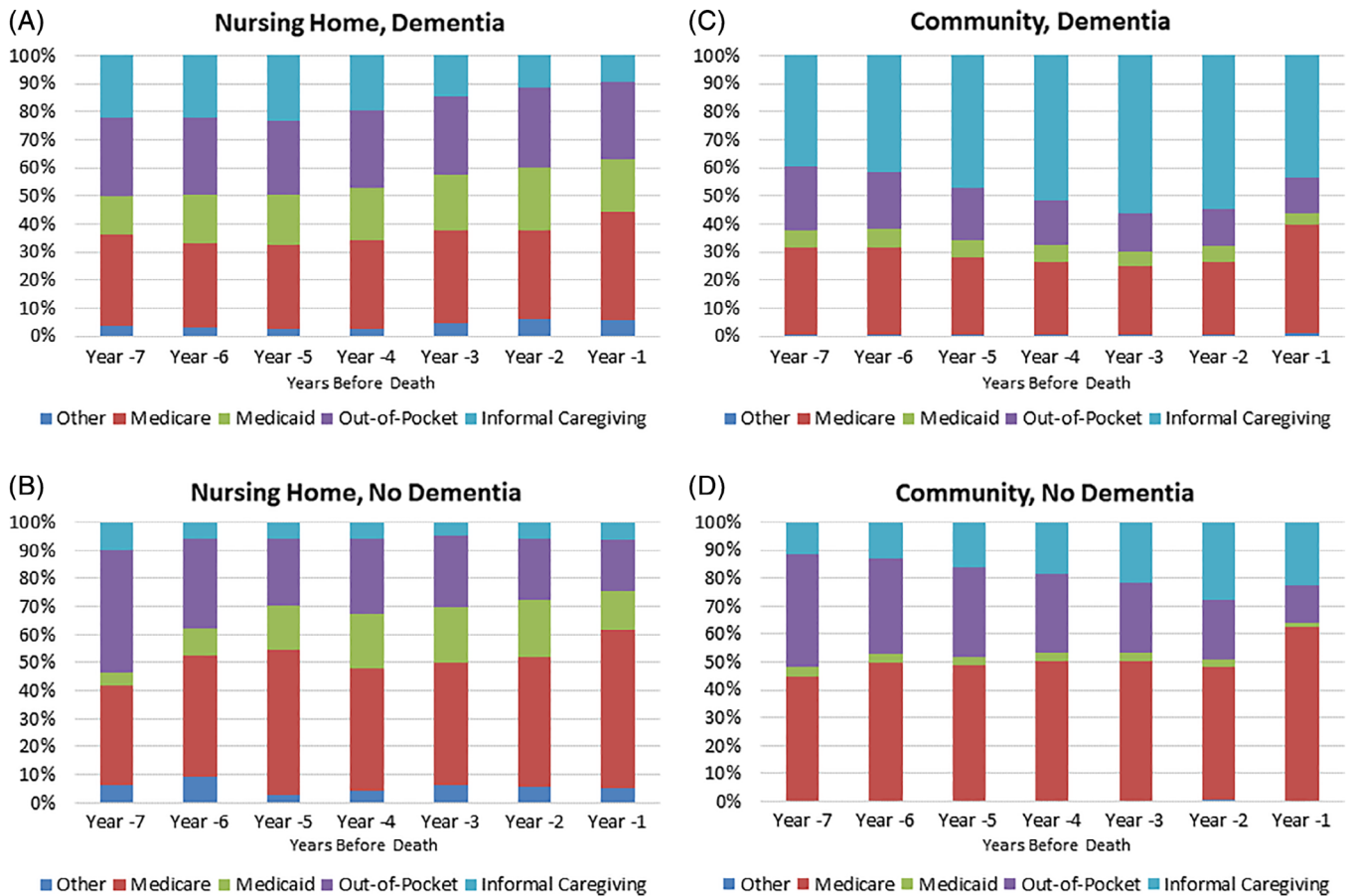


Figure 2. Proportion of spending by payer over last 7 years of life among nursing home and community residents, by dementia status. Authors’ analysis of data from the Health and Retirement Study, linked to Medicare and Medicaid claims data. (A) Nursing home, dementia (n = 519); (B) nursing home, no dementia (n = 114); (C) community, dementia (n = 675); (D) community, no dementia (n = 1601).

dementia, costs for nursing home residents were higher than those of non-nursing home residents (\$339,600 vs \$236,460), with families of community-dwelling participants providing \$49,480 in informal care (Figure 1).

Finally, we found differences in the temporal pattern of costs in relation to dementia status (Figure 2). Over the last 7 years of life, households of a person with dementia continuously support 50% to 60% of costs (out-of-pocket and informal caregiving costs combined); among those without dementia, their portion of support declines from 52% at baseline to 35% in the last year of life.

DISCUSSION

The burden of dementia on families in both caregiving time and out-of-pocket costs extends over many years. Here we go back 7 years before death and show that total spending across the 7-year period is markedly higher for those with dementia than among those without. The magnitude of cumulative costs among those with dementia, averaging more than \$370,000 per person, is substantial and not attributable distinctively to nursing home residence. Those with dementia living in the community accumulate equally high total spending. For community-dwelling older adults, as compared with the institutionalized population who are

often covered by Medicaid, a greater proportion of these costs is borne by families.

All families support a substantial proportion of health-related costs over the last 7 years of life, but among those with dementia this averages more than half of all cumulative costs. And although this study provided a longer observation period, the results reveal that differences in costs exist even at the beginning of the 7-year study period. These differences are initially small but already statistically significant with regard to Medicaid, informal caregiving, and thus total costs, which are higher among those with dementia in both nursing home and community settings. Additional research is needed to determine when these differences first emerge.

We also note that those with dementia are older and more likely to have comorbidities, yet adjusted sensitivity analyses found similar results. Although functional impairment may also contribute to higher costs and caregiving needs, we recognize disability is a characteristic of those living with dementia, and thus the descriptive and unadjusted spending presented is a more direct representation of the experience of these individuals and their families.¹⁹

These results must be interpreted with several limitations in mind. We were unable to measure costs from other private payers and VA sources directly. Additionally, by requiring 7 years of fee-for-service Medicare coverage, the

sample excludes those dying at younger ages, who may experience different spending patterns, as well as those covered under Medicare Advantage. Furthermore, a portion of Medicaid spending and the estimated costs of informal caregiving were imputed. We were also unable to assess lost wages for caregivers directly. Caregiving was only measured with regard to time because we were unable to assess the emotional or physical burdens of caregiving, and this study included no measures of care quality, goal congruence, or caregivers' preferences.

As healthcare policies, benefit redesign, and market factors interact to shift costs from one payer to another (and, for many, from governmental payers to families), we must understand the magnitude and impact of healthcare spending and its distribution across payers (including individuals and families) over time. The findings of this study demonstrate large disparities in care needs shouldered by families of those with dementia, compared with those without, in the context of current government programs and policies. They also highlight the particular burden faced by families of people with dementia who reside in the community, a population that is likely to grow in coming years.²⁰ Further research is needed to explore the relationships between spending burden and the quality of patient care, as well as the impact of this financial and caregiving burden on families.

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REFERENCES

- Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368(14):1326-1334.
- Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med*. 2015;163(10):729-736.
- Pyenson B, Sawhney TG, Steffens C, et al. The real-world Medicare costs of Alzheimer disease: considerations for policy and care. *J Manag Care Spec Pharm*. 2019;25(7):800-809.
- Friedman EM, Shih RA, Langa KM, Hurd MD. US prevalence and predictors of informal caregiving for dementia. *Health Aff (Millwood)*. 2015;34(10):1637-1641.
- Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *JAMA*. 1994;272(23):1839-1844.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-2219.
- Ornstein KA, Schulz R, Meier DE. Families caring for an aging America need palliative care. *J Am Geriatr Soc*. 2017;65(4):877-878.
- Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med*. 2000;132(6):451-459.
- Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff (Millwood)*. 2015;34(10):1642-1649.
- Thach NT, Wiener JM. U.S. Department of Health & Human Services. Office of the Assistant Secretary for Planning and Evaluation (ASPE). An Overview of Long-Term Services and Supports and Medicaid: Final Report. Washington, DC: US Department of Health and Human Services; 2018. <https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report>. Accessed March 9, 2020.
- Office of the Assistant Secretary for Planning and Evaluation. National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers. Washington, DC: US Department of Health and Human Services; 2018.
- Health and Retirement Study (2004-2015 survey data, with linked Medicare and Medicaid claims). Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant number NIA U01AG009740) and the Social Security Administration. <http://hrsonline.isr.umich.edu/>. Accessed March 9, 2020.
- Plassman B, Langa K, Fisher G, et al. Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology*. 2007;29(1-2):125-132.
- Langa KM, Plassman BL, Wallace RB, et al. The Aging, Demographics, and Memory Study: study design and methods. *Neuroepidemiology*. 2005;25(4):181-191.
- Kelley AS, McGarry K, Fahle S, Marshall SM, Du Q, Skinner JS. Out-of-pocket spending in the last five years of life. *J Gen Intern Med*. 2013;28(2):304-309.
- Marshall S, McGarry K, Skinner J. The risk of out-of-pocket health care expenditures at the end of life. In: Wise D, ed. *Explorations in the Economics of Aging*. Chicago, IL: University of Chicago Press; 2011.
- McGarry K, Schoeni R. Widow(er) poverty and out of pocket medical expenses near end of life. *J Gerontol B Psychol Sci Soc Sci*. 2005;60(3):S160-S168.
- Genworth, Genworth Cost of Care Survey. <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>. Accessed June 20, 2019.
- Chi W, Graf E, Hughes L, et al. Community-Dwelling Older Adults with Dementia and their Caregivers: Key Indicators from the National Health and Aging Trends Study. Washington, DC: US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation; 2019.
- Gaugler J, James B, Johnson T, Marin A, Weuve JJA. 2019 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2019;15(3):321-387.

SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Supplementary Table S1: Characteristics of decedents by Medicare fee-for-service (FFS) status.