

The Burden of Health Care Costs for Patients With Dementia in the Last 5 Years of Life

Amy S. Kelley, MD, MSHS; Kathleen McGarry, PhD; Rebecca Gorges, MA; and Jonathan S. Skinner, PhD

Background: Common diseases, particularly dementia, have large social costs for the U.S. population. However, less is known about the end-of-life costs of specific diseases and the associated financial risk for individual households.

Objective: To examine social costs and financial risks faced by Medicare beneficiaries 5 years before death.

Design: Retrospective cohort.

Setting: The HRS (Health and Retirement Study).

Participants: Medicare fee-for-service beneficiaries, aged 70 years or older, who died between 2005 and 2010 ($n = 1702$), stratified into 4 groups: persons with a high probability of dementia or those who died because of heart disease, cancer, or other causes.

Measurements: Total social costs and their components, including Medicare, Medicaid, private insurance, out-of-pocket spending, and informal care, measured over the last 5 years of life; and out-of-pocket spending as a proportion of household wealth.

Results: Average total cost per decedent with dementia (\$287 038) was significantly greater than that of those who died of heart disease (\$175 136), cancer (\$173 383), or other causes

(\$197 286) ($P < 0.001$). Although Medicare expenditures were similar across groups, average out-of-pocket spending for patients with dementia (\$61 522) was 81% higher than that for patients without dementia (\$34 068); a similar pattern held for informal care. Out-of-pocket spending for the dementia group (median, \$36 919) represented 32% of wealth measured 5 years before death compared with 11% for the nondementia group ($P < 0.001$). This proportion was greater for black persons (84%), persons with less than a high school education (48%), and unmarried or widowed women (58%).

Limitation: Imputed Medicaid, private insurance, and informal care costs.

Conclusion: Health care expenditures among persons with dementia were substantially larger than those for other diseases, and many of the expenses were uncovered (uninsured). This places a large financial burden on families, and these burdens are particularly pronounced among the demographic groups that are least prepared for financial risk.

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For author affiliations, see end of text.

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The recent reduction in Medicare growth rates, coupled with a decline in the fraction of the total U.S. health care bill paid out-of-pocket by patients, might suggest that U.S. health care (and Medicare, more specifically) is protecting older persons from catastrophic health care expenses (1-3). Yet little is known about the total social costs (personal out-of-pocket costs plus external or governmental costs [4]) and the household financial burdens of care in the last years of life. The evidence is limited to spending from only 1 insurance program (Medicare) (5, 6) or focuses only on out-of-pocket spending, whether as a fraction of total health spending (7) or in terms of dollars spent (8). One important study measured the differential effect of dementia on total health care costs (9), but the researchers did not quantify the financial risks faced by patients with dementia among vulnerable subgroups of the population and did not consider financial risks for persons who died of other diseases. Despite proposals to introduce voucher or premium support plans that could entail greater out-of-pocket cost sharing for older persons or shift expenses to other government or private payers (10-12), little is known about the extent of end-of-life, health-related financial risk faced by individual households or the overall cost burden to government and private health insurance.

Here, we consider the social costs and financial risks faced by Medicare beneficiaries during the 5 years before death. We consider various social costs associated with disease, such as government (Medicare and Medicaid) spending, private insurance, out-of-pocket expenditures, and informal care. We also examine how these spending components in the last 5 years of life vary across 4 disease groups: dementia, cancer, heart disease, and other conditions. To address this question, we use the HRS (Health and Retirement Study), which is a nationally representative longitudinal cohort study of U.S. adults older than 50 years funded by the National Institute on Aging. The HRS includes detailed information on out-of-pocket spending, total Medicare spending, insurance coverage, socioeconomic status, health and cognitive status, and cause of death.

METHODS

Serial "core" interviews are done every 2 years in the HRS, and response rates for each interview wave have exceeded 86%. These interviews include detailed

See also:

Summary for Patients. I-28

EDITORS' NOTES**Context**

Not enough is known about the cost of end-of-life care for persons with different medical conditions.

Contribution

The researchers found that Medicare patients with dementia had greater total costs and out-of-pocket costs for end-of-life care than Medicare patients with heart disease, cancer, or other conditions. Families of patients with dementia also had to pay a greater proportion of family assets for end-of-life care than families of patients without dementia.

Caution

Some costs were estimated.

Implication

The cost of end-of-life care is disproportionate for families of patients with dementia.

questions on the participant's demographic characteristics, social and functional characteristics, medical information, caregiving needs and hours of support, and financial information. The HRS also links patient survey data to individual Medicare claims records and the National Death Index. We sampled all HRS decedents identified by a postdeath proxy interview between 2006 and 2010 ($n = 4086$). We combined these data with each decedent's interview data (on average 2 interviews) from the previous 5 years.

To examine Medicare spending during the last 5 years of life, we excluded respondents younger than 70 years at the time of death ($n = 851$) and those who died outside of the study period of 1 January 2005 to 31 December 2010 ($n = 267$). We also excluded persons without linked Medicare claims data ($n = 113$), those who lacked continuous fee-for-service Medicare Parts A and B coverage during the 5 years preceding death ($n = 103$), and those who did not provide information about entitlement for the full 60 months before the date of death ($n = 75$). We were not able to use persons with Medicare Part C (that is, Medicare Advantage) because complete claims data for this group are not available ($n = 792$). Finally, we excluded persons who had no core interviews in the 5 years preceding death ($n = 77$), those with no dementia probability estimate ($n = 100$), and those who lived outside of the United States ($n = 6$). The final sample included 1702 persons.

Total out-of-pocket expenses were summed across all categories and scaled to comprise a consistent 60-month (5-year) period (8, 13). The study period was defined for each person by his or her date of death and the 60 months preceding that date. Because HRS surveys are done approximately every 2 years, the sum of months does not have to be exactly 60 months. As in our earlier study, when the spending reported in the HRS surveys exceeded the 60-month look-back period,

we adjusted spending to a 60-month period by prorating expenses and use reported in the earliest HRS interview—the period farthest from death and thus likely to have the lowest cost (8). For example, if the period covered by the HRS surveys comprised 64 months, with the earliest survey reflecting a 28-month (rather than a 24-month) period, we prorated the spending and use reported in that survey (by 24/28) to adjust total health care spending to a 60-month period.

Groups were determined as follows: Persons were assigned to the dementia group if the probability of dementia at the last available assessment (on average 24 months before death) exceeded 50%. This probability is provided by the HRS and reflects an algorithm formulated by its investigators that is based on multiple cognitive measures; methods are reported elsewhere (9, 14). We and others use this probabilistic approach because so few decedents are coded as having died of dementia—most are identified on death records as having died of something else. We did sensitivity tests using alternative probability cutoffs for defining the dementia group, specifically probabilities of 70% or greater and 90% or greater. Decedents in the nondementia group were assigned to 3 groups according to the cause of death obtained by the HRS from the National Death Index: cancer, heart disease, or other conditions.

Health-related out-of-pocket spending is measured every 2 years in the HRS core interviews and again in the postdeath interview, in which it is reported by the decedent's surviving spouse, family members, or other knowledgeable proxy. Specific categories of spending include insurance, hospital, physician, medication, nursing home, hired helpers, in-home medical care, and other expenses. We measured total Medicare expenditures in the last 5 years of life, including all claims for inpatient, outpatient, skilled-nursing facility, hospice, home care, and durable medical equipment. We collected data on other insurance coverage (Medicaid, private Medigap and long-term care policies, and Veterans Health Administration coverage) and household wealth from HRS surveys. When respondents did not know the exact amount spent on a specific item, they could instead report a range (for example, between \$2000 and \$10 000). In these cases, we followed the methods described by Marshall and colleagues (13) and used HRS data to impute a mean value for that individual.

The total number of nights spent in a nursing home was reported in the HRS interviews and summed across the 5 years preceding death. Using the average private payer cost of a night in a nursing home within the person's state (15), we first estimated the number of nights paid based on reported nursing home out-of-pocket spending. Using Medicare claims and Medicare expenditures data, we then accounted for the number of nights covered by Medicare. The remaining nights were attributed to either a private payer or Medicaid (adjusted to the lower state-based Medicaid price), based on whether the person was eligible for Medicaid

Table 1. Sample Characteristics, by Disease Group*

| Characteristic | Dementia (n = 555) | Cancer (n = 279) | Heart Disease (n = 431) | Other Conditions (n = 437) |
|--------------------------------------|-----------------------|---------------------|----------------------------|-------------------------------|
| Mean age at death (SD), y | 88.4 (6.4)† | 81.7 (6.3) | 84.8 (6.8) | 83.3 (6.7) |
| Black, % | 8.0 | 6.5 | 6.0 | 7.9 |
| Less than high school education, % | 46.8† | 29.4 | 28.9 | 34.8 |
| Women, % | | | | |
| Married at death | 9.0† | 14.1 | 11.7 | 11.2 |
| Unmarried at death | 59.1† | 40.4 | 44.3 | 40.6 |
| Men, % | | | | |
| Married at death | 16.5† | 30.1 | 23.2 | 28.3 |
| Unmarried at death | 15.4† | 15.5 | 20.8 | 20.0 |
| Medicaid, % | | | | |
| 5 y before death | 21.1† | 8.0 | 7.7 | 13.3 |
| At death | 48.5† | 19.8 | 21.5 | 28.2 |
| Mean probability of dementia (SD) | 0.87 (0.16)† | 0.09 (0.12) | 0.13 (0.14) | 0.12 (0.14) |
| Independent in ADL, %‡ | 49.8† | 88.7 | 85.2 | 82.6 |
| Self-rated health as fair/poor, %‡ | 53.9 | 41.5 | 43.2 | 54.7 |
| Currently smoke, %‡ | 2.8† | 15.2 | 8.3 | 9.2 |
| ≥4 self-reported conditions, % | 27.9 | 27.3 | 28.2 | 31.1 |
| Mean total payments of all types, \$ | 287 038† | 173 383 | 175 136 | 197 286 |
| Mean total government payments, \$ | 121 776† | 102 468 | 96 514 | 109 813 |
| Mean Medicare payments, \$ | 86 430† | 101 247 | 91 377 | 103 786 |
| Mean out-of-pocket expenses, \$ | 61 522† | 28 818 | 35 294 | 36 073 |
| Mean imputed informal care costs, \$ | 83 022† | 39 230 | 32 254 | 43 988 |

ADL = activities of daily living.

* Dementia group defined by a probability of dementia >0.5; cancer, heart disease, and other conditions groups defined by cause of death from National Death Index; HRS (Health and Retirement Study) household sample weighting was used.

† Significantly different ($P < 0.010$) for dementia decedents compared with all other decedents.

‡ HRS data, an average of 5 y before death.

at that time. This imputation procedure has been described separately (9).

To account for the implicit cost of caregiving beyond that paid by Medicare for home health service and out-of-pocket spending for hired helpers, we followed a previous study by converting the participants' reported hours of informal care provided in the month before each interview to a 5-year total number of hours and multiplied this by the state's average costs of home health care services (mean, \$20 per hour; range, \$16 to \$28) (15). For sensitivity analysis, we replaced the state-based costs of nursing home (Medicaid and private payer) and home health care with the national averages. All measures of health care use and spending are therefore derived from individual Medicare claims data or self-reported data in the HRS. Where costs are not explicitly reported, we have used the validated imputation methods previously described to assign values.

We adjusted all expenditures for inflation (2010 U.S. dollars) based on the Consumer Price Index. We discounted spending to 5 years before death using a 3% discount rate. To compare the relative burden of out-of-pocket spending by household, we calculated the median of the ratio of discounted real out-of-pocket spending 5 years before death and divided this by household wealth, as measured closest to the fifth year before death. For sensitivity analysis, we also calculated this ratio for financial wealth, which excluded the equity value of the house. All reported values are adjusted for HRS sampling weights using the most recent weight available for each person (13).

We considered the patterns of spending associated with sociodemographic factors in 2 ways. In our primary results, we examined spending across diseases

and subgroups based on race, marital status, and education. Because patients with dementia are often older and have lower educational attainment, we also considered spending measures by disease (dementia and nondementia groups) and we adjusted these measures for age (5-year intervals), sex, race, education, marital status, and common coexisting conditions (stroke, diabetes, heart disease, hypertension, lung disease, cancer, psychiatric problems, and arthritis) using a γ -distribution regression model.

Role of the Funding Source

The study was approved by the Mount Sinai School of Medicine Institutional Review Board, HRS Data Confidentiality Committee, and Centers for Medicare & Medicaid Services Privacy Board. The HRS is funded by the National Institute of Aging (NIA) and the Social Security Administration. The study investigators also received support from the NIA and the American Federation for Aging Research. Funding sources had no role in the design, conduct, and analysis of this study or in the decision to submit the manuscript for publication.

RESULTS

The dementia group included 555 participants with a greater than 50% probability of having dementia in the 5 years preceding death. The mean probability of dementia among this group was 87%; further, 59% of this group had probabilities of dementia greater than 90%. For the remaining participants ($n = 1147$), the mean probability of dementia was 12%. The primary causes of death among the nondementia group included cancer ($n = 279$), heart disease ($n = 431$), or

Table 2. Spending by Dementia and Other Disease Groups, Across Payers, as a Proportion of Wealth and by Subgroups

| Characteristic | Participants, n | Mean (Median), \$ | | | | | Median Out-of-Pocket Spending as Percentage of Wealth* |
|---------------------------------------|--------------------|------------------------|--------------------------|---------------------------|-------------------------------|-------------------|--|
| | | Total Social Costs† | Medicare and Medicaid | Implicit Costs of Care | Out-of-Pocket Expenditures | Wealth | |
| Dementia | 555 | 287 038 (257 200) | 121 776 (90 473) | 83 022 (26 560) | 61 522 (36 919) | 340 182 (115 942) | 32.2 |
| Black | 72 | 296 239 (260 560) | 152 992 (118 822) | 117 496 (58 376) | 23 425 (10 969) | 47 306 (25 597) | 83.6 |
| Nonblack | 483 | 286 241 (257 200) | 119 074 (89 906) | 80 038 (25 263) | 64 819 (40 410) | 365 534 (147 412) | 31.8 |
| Less than high school education | 276 | 287 342 (261 746) | 129 572 (102 749) | 98 856 (35 854) | 44 378 (20 786) | 194 904 (52 647) | 47.5 |
| High school diploma or higher | 278 | 287 604 (251 176) | 114 769 (83 917) | 69 504 (18 895) | 77 004 (53 164) | 465 622 (193 894) | 24.3 |
| Women | | | | | | | |
| Married | 46 | 335 573 (297 840) | 109 500 (90 473) | 177 767 (97 025) | 41 381 (26 263) | 716 177 (316 907) | 7.4 |
| Not married | 339 | 287 314 (258 937) | 129 280 (91 272) | 68 625 (15 286) | 66 215 (37 951) | 242 036 (84 235) | 58.2 |
| Men | | | | | | | |
| Married | 85 | 284 131 (243 766) | 110 083 (84 084) | 108 524 (54 518) | 52 655 (37 547) | 518 683 (284 996) | 13.8 |
| Not married | 85 | 260 843 (224 654) | 112 683 (102 285) | 55 755 (18 094) | 64 750 (29 463) | 306 376 (81 314) | 36.4 |
| Other disease groups | 1147 | 183 001 (151 693) | 102 878 (81 945) | 38 272 (8566) | 34 068 (24 684) | 519 302 (220 415) | 11.4 |
| Black | 119 | 219 446 (192 934) | 133 002 (110 650) | 65 569 (18 596) | 17 790 (13 056) | 128 453 (57 971) | 29.5 |
| Nonblack | 1028 | 180 347 (148 496) | 100 684 (80 156) | 36 284 (8115) | 35 254 (25 353) | 547 770 (247 932) | 10.8 |
| Less than high school education | 377 | 187 794 (163 329) | 108 075 (88 726) | 49 983 (13 178) | 24 342 (18 968) | 217 132 (83 189) | 20.9 |
| High school diploma or higher | 768 | 180 818 (145 130) | 100 466 (78 668) | 32 948 (6627) | 38 525 (27 364) | 657 195 (315 180) | 9.4 |
| Women | | | | | | | |
| Married | 134 | 214 643 (198 092) | 102 282 (92 900) | 65 136 (34 029) | 40 786 (31 727) | 631 137 (348 598) | 9.7 |
| Not married | 473 | 180 513 (151 693) | 106 793 (81 380) | 25 126 (6589) | 37 182 (25 003) | 308 272 (128 623) | 21.1 |
| Men | | | | | | | |
| Married | 321 | 197 552 (153 785) | 109 862 (82 778) | 56 450 (14 496) | 28 576 (22 387) | 743 480 (370 635) | 6.4 |
| Not married | 219 | 148 439 (122 327) | 85 038 (62 411) | 24 918 (4188) | 30 678 (22 432) | 598 714 (263 937) | 10.1 |

* Out-of-pocket spending as a percentage of wealth was calculated for each participant, then reported as the groups' median ratio. Spending was adjusted to 2010 dollars for inflation and discounted to 5 y before death. HRS (Health and Retirement Study) weights were used.

† Imputed third-party payments for nursing home costs were included in total social costs but were not listed here separately.

other conditions ($n = 437$) (Table 1). The dementia group was older at the time of death (88 years compared with 82, 85, and 83 years in the cancer, heart disease, and other conditions groups, respectively), was less likely to be married (25% compared with 44%, 35%, and 39%, respectively), and had lower median household wealth at the beginning of the study period (\$115 942 compared with \$243 168, \$203 748, and \$220 771, respectively). In addition, Medicaid enrollment was significantly higher among the dementia group at the start of the study period (21% compared with 8%, 8%, and 13%, respectively) and enrollment increased during the last 5 years of life (27% compared with 12%, 15%, and 15%, respectively).

The mean adjusted total health care spending in the last 5 years of life was \$287 038 among decedents with dementia and \$183 001 among those in other disease groups (Table 2). The mean adjusted total Medicare spending 5 years before death was similar across groups: \$86 430 and \$98 326 in the dementia and nondementia groups, respectively. However, average Medicaid, out-of-pocket, and informal care costs were higher for the dementia group (\$35 346, \$61 522, and \$83 022, respectively) than for the nondementia group (\$4552, \$34 068, and \$38 272, respectively). Absolute out-of-pocket spending was significantly higher in the

dementia group, and such spending as a proportion of total household wealth 5 years before death was also substantially higher (median, 32% [dementia group] and 11% [nondementia group]). Out-of-pocket spending as a ratio of financial wealth (that is, excluding housing) was even larger (median, 242% [dementia group] and 81% [nondementia group]). Subcategories of out-of-pocket spending are not reported here, but their patterns are consistent with those reported in our earlier work (8).

In stratified analyses, the gap in out-of-pocket financial burdens between decedents with and without dementia was more pronounced for lower education and minority groups. Among persons with dementia and less than a high school education, median out-of-pocket spending accounted for almost half (48%) of wealth 5 years before death compared with 21% for those without dementia (Table 2). This difference was not as marked among those with a high school education or higher (median out-of-pocket spending, 24% and 9%, respectively). In addition, women with dementia who were unmarried at the time of death spent 58% of their wealth on out-of-pocket health-related costs, whereas those without dementia spent 21% and those with a surviving spouse spent 10% or less, regardless of dementia status. Black decedents in the dementia

group spent even more wealth on out-of-pocket health-related costs (84%) than black decedents in the non-dementia group (30%).

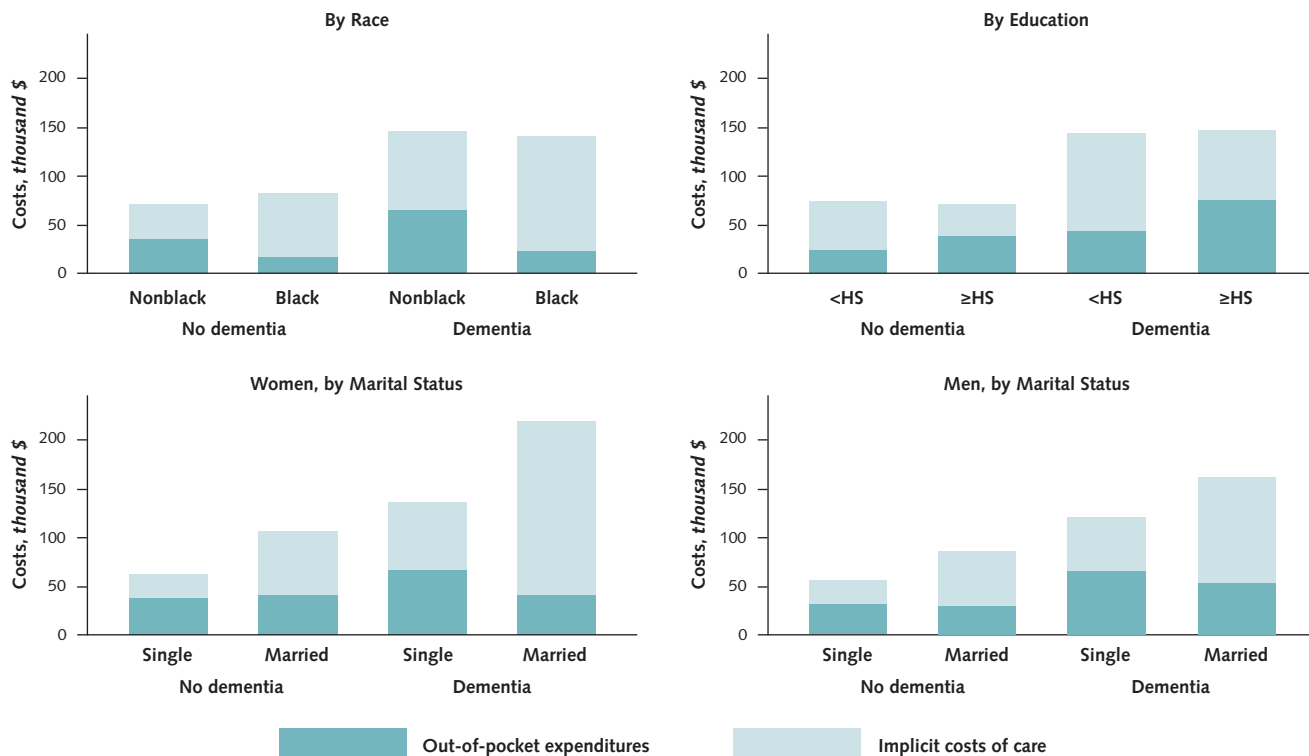
Implicit costs of informal care varied considerably across sociodemographic subgroups. Average informal care for decedents with dementia (\$83 022) was more than double the corresponding care for those without dementia (\$38 272) ($P < 0.001$). For various subgroups, **Figure 1** shows the combined out-of-pocket and implicit informal costs faced by families providing end-of-life care. Black decedents at high risk for dementia had much lower levels of out-of-pocket spending (\$23 425) than nonblack decedents (\$64 819), most likely because of fewer financial resources (**Table 2**). However, more informal care was provided in black households (\$117 496) than in nonblack households (\$80 038) ($P < 0.001$), so the combined value of out-of-pocket spending and informal care was nearly identical between the 2 groups. Further, a similar pattern of higher out-of-pocket spending and lower implicit informal care costs was also found for high school graduates compared with those who did not finish high school. Despite finding a marked tradeoff between out-of-pocket spending (higher among nonblack persons and high school graduates) and informal care costs (higher among black persons and those with lower educational attainment), the total value of these 2 spending categories was similar across race and education groups.

Combined informal and out-of-pocket expenses, however, were substantially higher in married households. **Figure 1** shows that out-of-pocket expenditures were slightly lower for married decedents with dementia than for unmarried decedents, but the costs of informal care were more than double for married women in the dementia group (\$177 767 compared with \$65 136 for married women at low risk for dementia). Similar patterns were seen in men. As a result, combined expenses (informal plus out-of-pocket) were considerably higher for married decedents than for those who were single.

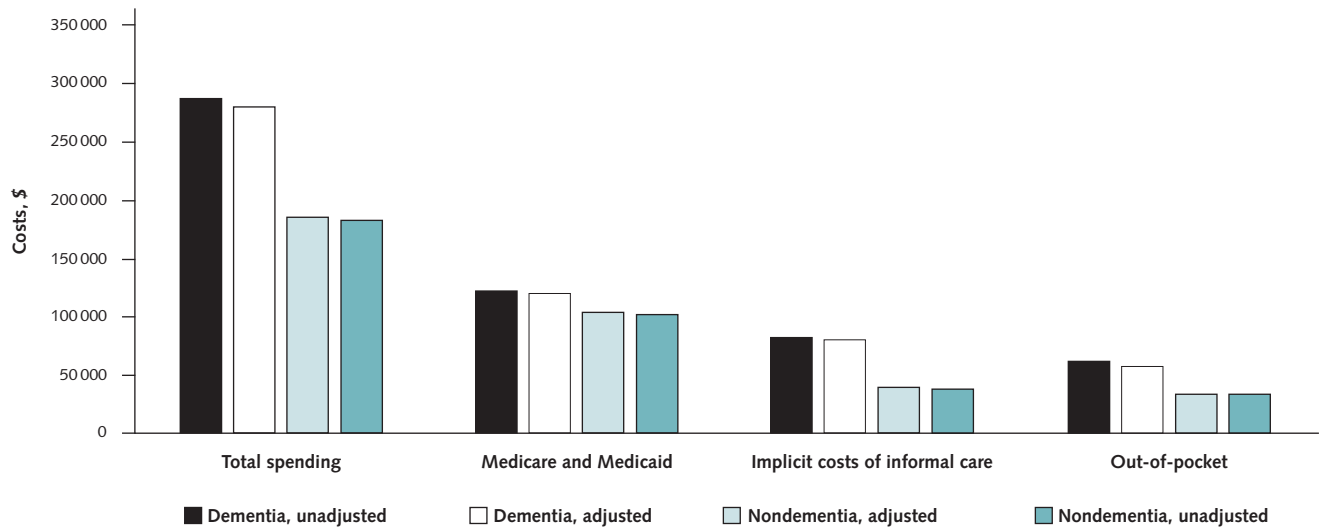
Figure 2 presents estimates of total spending for the dementia and nondementia groups, adjusted for age, sex, race, education, marital status, and coexisting conditions using a γ -distribution regression model (**Appendix Table 1**, available at www.annals.org). The adjusted overall spending for patients with dementia, \$279 076, is closer to the adjusted spending for those without dementia, \$185 801, with a gap of \$93 275 over the entire 5-year period.

Finally, in sensitivity analyses using alternative cut-offs for defining the dementia group, we found that the same pattern of results held whether we limited the group to persons with a risk for dementia of 70% or greater ($n = 456$ vs. $n = 555$ [original sample]) or 90% or greater ($n = 329$) (**Appendix Table 2**, available at www.annals.org). Sensitivity analyses using the national (instead of state) average prices for nursing home and

Figure 1. Out-of-pocket expenses and implicit costs of informal care, by dementia and demographic subgroups.



HS = high school.

Figure 2. Adjusted and unadjusted end-of-life spending for dementia and nondementia groups.

caregiving costs produced slightly higher cost estimates for all disease groups and categories of spending, although the pattern of spending was unchanged.

DISCUSSION

We used the nationally representative HRS cohort to examine the total health care spending of beneficiaries who died at age 70 years or older. Over the last 5 years of life, total social costs for persons with dementia were more than \$250 000 per person, which is 57% greater than the social costs associated with death from other diseases. Further, the financial burden for patients with dementia was greater than that for persons with other diseases in terms of out-of-pocket spending (in absolute terms and as a percentage of household wealth) and the implicit costs of informal caregiving. This gap in the financial burden between persons at high and low risk for dementia was larger in the groups most vulnerable to financial risk: those who were unmarried, were black, and had less than a high school education. Of note, the dementia group already had markedly less wealth and a greater percentage was enrolled in Medicaid, a proportion that only grew over time. This may be the result of care needs and expenses occurring before our 5-year look-back period.

Medicare provides nearly universal health care coverage for U.S. adults older than 65 years. However, it does not cover the health-related expenses most valuable to those with chronic diseases or life-limiting illnesses, such as home care services, equipment, and nonrehabilitative nursing home care. These uncovered (uninsured) needs are greatest among persons with dementia, which is a chronic disease characterized by many years of progressive functional decline and supportive care needs. Our findings clearly show that the predominant determinant of health care costs for the

dementia group are nursing home and informal care costs, and these burdens are largely borne by individuals and families, particularly among vulnerable subgroups. This leads to more than half of all patients with dementia having “spent down” sufficiently to qualify for Medicaid by their time of death, including three quarters of persons belonging to racial minorities. Despite the presence of Medicaid, families of decedents with dementia who were black or who had lower educational attainment faced a larger burden of informal caregiving (16, 17).

In a pioneering study of dementia costs, Hurd and colleagues (9) used a similarly broad measure of costs associated with caring for persons with dementia from the HRS cohort. They found that raising the probability of dementia from 0% to 100% leads to annual additional social costs between \$41 689 and \$56 290 per person per year, depending on the imputation method (9). Our estimated differential cost for the dementia group, \$93 275 over 5 years, is considerably smaller than their annual estimate for 2 reasons. First, their measure is a hypothetical assignment that raises the probability of dementia from 0% to 100%. In contrast, we compare groups (nondementia and dementia) with a mean probability of dementia of 12% and 87%, respectively. Weighting their figures accordingly would reduce their estimates of dementia costs to between \$31 267 and \$42 218 annually, which is closer to, but still higher than, our estimates expressed on an annual basis. A more important explanation for the difference is that we are comparing dementia and nondementia groups in the last 5 years of life. Because members of our nondementia group were all within 5 years of death, they were probably sicker than the nondementia control group in the study by Hurd and colleagues, leading to a smaller difference in costs between the 2

groups. Our study emphasizes that all households face substantial financial risks near the end of life, regardless of disease; however, households with patients with dementia face even larger risks, especially out-of-pocket and implicit costs of caregiving.

This study has several limitations. First, because of data restrictions we do not have direct measures of Medicaid or private insurance payments for the decedents. The methods we used to impute these payers' expenses are limited to coverage for nursing home care and probably underrepresent actual spending. Although we capture private insurance premiums in our measure of out-of-pocket spending, these do not reflect the tremendous variability across our sample in the dollar amounts paid by private insurance for health care services. In addition, we do not have information on lost wages because of illness. Few of our decedents were still working 5 years before death, but caregivers may be forgoing job opportunities that pay considerably more on an hourly basis than what we imputed using home health care service rates.

Second, we measured only the probability of dementia and not whether the person actually had dementia. In theory, death certificate data could be used, but in practice, relatively few death certificates list dementia as the primary cause; instead, the cause of death reflects the more immediate diagnosis, such as pneumonia. To the extent that we included patients with true dementia in the nondementia group, the differences we found between the disease categories are understated. Finally, we were not able to measure the true value of the services or care provided to the patient, rather only the dollars spent.

Despite the slowing of growth in Medicare spending and a declining share of out-of-pocket expenditures during the 2000s, we find older persons facing large and highly variable expenditures as they approach the last years of life. Household health-related financial risk is greatest among the social groups least able to cope, which further contributes to the poverty of surviving spouses and a continued intergenerational cycle of poverty (18, 19). Vast differences in spending by disease complicate the ability of individuals and families to plan and save for future health care expenses (8). Ongoing discussion of Medicare policy and health care reform should acknowledge the considerable financial risk currently faced by aging Medicare beneficiaries and examine reforms that might mitigate these risks.

From Icahn School of Medicine at Mount Sinai, New York, New York; University of California, Los Angeles, Los Angeles, California; and Dartmouth College, Hanover, New Hampshire.

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Reproducible Research Statement: *Study protocol:* Not available. *Statistical code:* Available from Dr. Kelley (e-mail, amy.kelley@mssm.edu). *Data set:* Available only by application for restricted data use from the HRS (<http://hrsonline.isr.umich.edu/index.php?p=resdat>) and Centers for Medicare & Medicaid Services (<http://hrsonline.isr.umich.edu/index.php?p=medicare>).

Requests for Single Reprints: Amy S. Kelley, MD, MSHS, Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, 1 Gustave L. Levy Place, Box 1070, New York, NY 10029; e-mail, amy.kelley@mssm.edu.

Current author addresses and author contributions are available at www.annals.org.

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Current Author Addresses: Dr. Kelley and Ms. Gorges: Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, 1 Gustave L. Levy Place, Box 1070, New York, NY 10029.

Dr. McGarry: Department of Economics, University of California, Los Angeles, 8283 Bunche Hall, Box 951477, Los Angeles, CA 90095.

Dr. Skinner: Department of Economics, Dartmouth College, 6106 Rockefeller Hall, Hanover, NH 03755.

Author Contributions: Conception and design: A.S. Kelley, K. McGarry, J.S. Skinner.

Analysis and interpretation of the data: A.S. Kelley, K. McGarry, R. Gorges, J.S. Skinner.

Drafting of the article: A.S. Kelley, K. McGarry.

Critical revision of the article for important intellectual content: A.S. Kelley, K. McGarry, J.S. Skinner.

Final approval of the article: A.S. Kelley, K. McGarry, J.S. Skinner.

Provision of study materials or patients: A.S. Kelley.

Statistical expertise: K. McGarry, J.S. Skinner.

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Administrative, technical, or logistic support: A.S. Kelley, J.S. Skinner.

Collection and assembly of data: A.S. Kelley, K. McGarry, R. Gorges.

Appendix Table 1. Adjusted Estimates of Predicted Spending and Marginal Effects by Dementia and Nondementia Groups*

| Characteristic | Mean (95% CI), \$ | | | | |
|--------------------------|------------------------------|------------------------------|----------------------------|------------------------------|---------------------------------|
| | Total Social Costs | Medicare and Medicaid | Implicit Costs of Care | Out-of-Pocket Expenditures | Wealth |
| Dementia | | | | | |
| Predicted spending | 279 076 (263 019 to 295 132) | 120 096 (111 357 to 128 834) | 79 931 (66 709 to 93 154) | 57 916 (52 306 to 63 527) | 437 015 (339 311 to 534 720) |
| Marginal effects | | | | | |
| Age 75-79 y | 18 520 (-16 034 to 53 074) | -9745 (-31 294 to 11 804) | 21 998 (-2802 to 46 797) | 9182 (-771 to 19 135) | 74 911 (-84 572 to 234 394) |
| Age 80-84 y | -64 (-33 610 to 33 481) | -24 367 (-45 419 to -3315) | 15 637 (-7519 to 38 793) | 12 237 (2225 to 22 249) | 110 692 (-51 166 to 272 550) |
| Age 85-89 y | 1985 (-30 949 to 34 920) | -27 442 (-48 173 to -6710) | 20 100 (-2672 to 42 871) | 12 897 (3170 to 22 624) | 62 293 (-86 922 to 211 509) |
| Age ≥90 y | 36 254 (1045 to 71 463) | -26 108 (-47 689 to -4527) | 27 141 (2488 to 51 794) | 26 306 (15 291 to 37 321) | 172 257 (1883 to 342 631) |
| Hispanic | 25 624 (-25 280 to 76 528) | 28 657 (-1565 to 58 879) | 41 191 (-13 684 to 96 065) | -29 852 (-39 401 to -20 303) | -325 610 (-438 651 to -212 569) |
| Black | 42 086 (3142 to 81 030) | 30 412 (8264 to 52 561) | 50 884 (9059 to 92 710) | -26 853 (-34 840 to -18 866) | -341 125 (-438 845 to -243 404) |
| Other race | -10 431 (-74 018 to 53 156) | -6351 (-38 989 to 26 286) | 5135 (-49 515 to 59 786) | -27 019 (-40 993 to -13 044) | -377 854 (-496 824 to -258 885) |
| Female | 35 602 (16 379 to 54 825) | 11 881 (1496 to 22 266) | 9188 (-6256 to 24 633) | 7108 (451 to 13 765) | -145 450 (-255 014 to -35 886) |
| Married | 60 451 (38 388 to 82 513) | 3022 (-8037 to 14 080) | 81 044 (56 068 to 106 020) | -2558 (-9521 to 4404) | 256 303 (129 173 to 383 433) |
| High school | -3985 (-23 395 to 15 425) | -5245 (-15 712 to 5222) | -24 060 (-40 743 to -7378) | 18 416 (12 015 to 24 818) | 221 133 (131 488 to 310 778) |
| College or higher | 30 259 (815 to 59 704) | 21 (-14 979 to 15 022) | -21 781 (-43 594 to 32) | 34 275 (22 305 to 46 244) | 568 069 (322 017 to 814 121) |
| Stroke | 84 698 (57 173 to 112 222) | 36 014 (21 316 to 50 711) | 45 861 (20 467 to 71 255) | -195 (-8364 to 7975) | -52 879 (-165 174 to 59 416) |
| Diabetes | 60 876 (36 724 to 85 027) | 32 815 (19 701 to 45 929) | 14 170 (-5027 to 33 367) | -1046 (-8381 to 6289) | -100 138 (-197 783 to -2493) |
| Heart disease | 24 945 (6937 to 42 954) | 19 445 (9720 to 29 171) | 1506 (-12 899 to 15 912) | 2492 (-3772 to 8757) | -53 806 (-143 266 to 35 654) |
| Hypertension | 7528 (-10 806 to 25 863) | -820 (-10 658 to 9019) | 5182 (-9689 to 20 053) | 1993 (-4415 to 8400) | -138 964 (-246 534 to -31 393) |
| Lung disease | 59 (-24 124 to 24 242) | 6356 (-7011 to 19 724) | 8465 (-12 093 to 29 023) | -14 325 (-21 427 to -7223) | -74 014 (-188 267 to 40 240) |
| Cancer | 1271 (-19 876 to 22 418) | 10 602 (-11 92 to 22 395) | -7358 (-23 315 to 8600) | 1019 (-6500 to 8537) | 84 754 (-37 241 to 206 749) |
| Psychological condition | 60 219 (35 074 to 85 364) | 22 996 (9783 to 36 208) | 20 369 (-424 to 41 162) | 6821 (-1493 to 15 134) | -61 625 (-168 846 to 45 597) |
| Arthritis | 21 857 (3163 to 40 551) | 15 591 (5870 to 25 313) | 9670 (-5380 to 24 720) | -4911 (-11 842 to 20 19) | -37 619 (-138 783 to 63 545) |
| Nondementia group | | | | | |
| Predicted spending | 185 801 (178 462 to 193 141) | 103 627 (98 536 to 108 718) | 39 393 (34 665 to 44 122) | 35 018 (32 637 to 37 400) | 484 046 (416 207 to 551 886) |
| Marginal effects | | | | | |
| Age 75-79 y | 12 330 (-10 677 to 35 337) | -8409 (-26 986 to 10 169) | 10 841 (-1227 to 22 910) | 5552 (-458 to 11 561) | 82 973 (-93 599 to 259 545) |
| Age 80-84 y | -43 (-22 376 to 22 291) | -21 026 (-38 916 to -3135) | 7707 (-3885 to 19 298) | 7399 (1272 to 13 526) | 122 604 (-58 712 to 303 920) |
| Age 85-89 y | 1322 (-20 618 to 23 261) | -23 679 (-41 235 to -6122) | 9906 (-1498 to 21 310) | 7798 (1837 to 13 759) | 68 997 (-98 566 to 236 560) |
| Age ≥90 y | 24 137 (361 to 47 912) | -22 528 (-40 694 to -4361) | 13 376 (870 to 25 883) | 15 905 (8903 to 22 908) | 190 795 (-6106 to 387 696) |
| Hispanic | 17 060 (-16 806 to 50 925) | 24 727 (-1331 to 50 786) | 20 301 (-6414 to 47 015) | -18 050 (-23 733 to -12 367) | -360 652 (-465 888 to -255 416) |
| Black | 28 020 (2092 to 53 947) | 26 242 (7113 to 45 371) | 25 078 (4566 to 45 590) | -16 237 (-20 894 to -11 579) | -377 836 (-463 110 to -292 562) |
| Other race | -6945 (-49 271 to 35 381) | -5480 (-33 615 to 22 654) | 2531 (-24 429 to 29 491) | -16 337 (-24 783 to -7890) | -418 519 (-522 649 to -314 388) |
| Female | 23 703 (10 814 to 36 592) | 10 252 (1239 to 19 264) | 4528 (-3235 to 12 292) | 4298 (281 to 8315) | -161 103 (-273 396 to -48 810) |
| Married | 40 247 (25 764 to 54 729) | 2607 (-6922 to 12 137) | 39 942 (28 392 to 51 492) | -1547 (-5771 to 2677) | 283 886 (150 612 to 417 160) |
| High school | -2653 (-15 595 to 10 289) | -4526 (-13 596 to 4544) | -11 858 (-20 219 to -3497) | 11 135 (7440 to 14 831) | 244 931 (160 543 to 329 319) |
| College or higher | 20 146 (730 to 39 562) | 18 (-12 925 to 12 962) | -10 735 (-21 578 to 109) | 20 724 (13 897 to 27 551) | 629 204 (394 202 to 864 207) |
| Stroke | 56 390 (37 448 to 75 332) | 31 075 (17 888 to 44 262) | 22 602 (9291 to 35 914) | -118 (-5055 to 4820) | -58 570 (-180 340 to 63 200) |
| Diabetes | 40 529 (24 442 to 56 617) | 28 315 (16 998 to 39 633) | 6983 (-2525 to 16 492) | -633 (-5067 to 3802) | -110 914 (-216 257 to -5572) |
| Heart disease | 16 608 (4680 to 28 536) | 16 779 (8490 to 25 067) | 742 (-6359 to 7844) | 1507 (-2274 to 5288) | -59 597 (-157 671 to 38 478) |
| Hypertension | 5012 (-7154 to 17 179) | -707 (-9203 to 7789) | 2554 (-4706 to 9814) | 1205 (-2655 to 5065) | -153 919 (-269 629 to -38 208) |
| Lung disease | 39 (-16 061 to 16 140) | 5485 (-6020 to 16 990) | 4172 (-5872 to 14 215) | -8661 (-13 000 to -4323) | -81 979 (-208 529 to 44 571) |
| Cancer | 846 (-13 229 to 14 921) | 9148 (-973 to 19 268) | -3626 (-11 562 to 4310) | 616 (-3926 to 5157) | 93 875 (-39 452 to 227 202) |
| Psychological condition | 40 093 (23 208 to 56 977) | 19 842 (8285 to 31 399) | 10 039 (-259 to 20 336) | 4124 (-927 to 9175) | -68 257 (-184 059 to 47 546) |
| Arthritis | 14 552 | 13 453 | 4766 | -2970 | -41 667 |

* Distribution = γ ; link = log; uses HRS (Health and Retirement Study) weighting. Average marginal effect and 95% CIs reported. References groups: age 70-74 y, male, white, not married, less than high school education.

Appendix Table 2. Sensitivity Analyses Using a Range of Dementia Probability Cut Points

| Variable | Participants, <i>n</i> | Total Social Costs, \$ | Medicare and Medicaid, \$ | Implicit Costs of Care, \$ | Out-of-Pocket Expenditures, \$ | Wealth, \$ | Out-of-Pocket as Percentage of Wealth |
|------------------------------|---------------------------|---------------------------|------------------------------|-------------------------------|-----------------------------------|------------|---|
| Dementia probability >50 = 1 | 555 | 287 038 | 121 776 | 83 022 | 61 522 | 340 182 | 32.2 |
| Median | | 257 200 | 90 473 | 26 560 | 36 919 | 115 942 | |
| Dementia probability >50 = 0 | 1147 | 183 001 | 102 878 | 38 272 | 34 068 | 519 302 | 11.4 |
| Median | | 151 693 | 81 945 | 8566 | 24 684 | 220 415 | |
| Dementia probability >70 = 1 | 456 | 300 773 | 125 262 | 87 819 | 65 224 | 327 519 | 38.7 |
| Median | | 271 643 | 91 776 | 29 920 | 40 410 | 109 506 | |
| Dementia probability >70 = 0 | 1246 | 186 196 | 103 097 | 40 051 | 34 882 | 509 804 | 11.8 |
| Median | | 155 254 | 82 132 | 8469 | 24 980 | 213 396 | |
| Dementia probability >90 = 1 | 329 | 317 350 | 127 521 | 89 648 | 75 214 | 344 586 | 47.5 |
| Median | | 292 643 | 91 272 | 27 338 | 49 883 | 105 294 | |
| Dementia probability >90 = 0 | 1373 | 192 709 | 104 584 | 43 982 | 35 267 | 489 047 | 12.3 |
| Median | | 160 985 | 82 778 | 9842 | 24 975 | 203 748 | |