The Burden of Health Care Costs in the Last 5 Years of Life

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Abstract

Background—Common diseases, particularly dementia, entail large social costs, previously well described for the U.S. population. Less is known about 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 five years before death.

Design—Retrospective cohort.

Setting—Health and Retirement Study.

Participants—Medicare fee-for-service beneficiaries, aged 70 years or older, who died 2005-2010 (N = 1702), stratified into four cohorts: individuals with high probability of dementia, or with either heart disease, cancer, or other causes of death.

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

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Results—Average total cost per decedent for dementia ($287,038) was significantly greater than for those who died of heart disease ($175,136), cancer ($173,383), or other causes ($197,286), p<0.001. While Medicare expenditures were similar across groups, average out-of-pocket spending for dementia patients ($61,522) was 81% higher than for non-dementia patients ($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 five years before death, compared to 11% for non-dementia decedents (p<0.001). This proportion was greater for Blacks (84%), those with less than high school education (48%), and unmarried/widowed women (58%).

Limitations—Imputed Medicaid, private insurance and informal care costs

Conclusions—Healthcare expenditures among those with dementia were substantially larger than for other diseases, with much of those expenses uninsured, thus placing a large financial burden on families. These burdens are particularly pronounced among demographic groups least prepared for financial risk.

Introduction

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 the elderly against catastrophic health care expenses(1-3). Yet little is known about the total social costs (i.e., 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 just one insurance program (e.g., Medicare)(5, 6); or only focuses 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 impact of a specific disease, dementia, on total health care costs(9), but did not quantify the financial risks faced by dementia patients and their families, nor did they consider financial risks for individuals who died of other diseases. Despite proposals to introduce voucher or premium support plans that could entail greater out-of-pocket cost-sharing for the elderly or shift expenses to other government or private payers(10-12), little is currently known about the extent of late life, health-related, financial risk faced by individual households, or the overall cost burden to government and private health insurance.

In this paper, we consider the social costs and financial risks faced by Medicare beneficiaries during the five years prior to death. We consider a variety of social costs associated with disease, such as government (Medicare and Medicaid) spending, private insurance, out-of-pocket expenditures, and informal care, and examine how these spending components in the last 5 years of life vary across four different disease groups: dementia, cancer, heart disease and other conditions. To address this question, we use the Health and Retirement Study (HRS), a rich longitudinal cohort study of U.S. adults age 50 years and older that includes detailed information on out-of-pocket spending and total Medicare spending, as well as information about insurance coverage, socioeconomic status, health and cognitive status, and cause of death.

Methods

The HRS is a National Institute on Aging-funded, ongoing longitudinal and nationally-representative cohort study of adults over the age of 50 years. Serial "core" interviews are conducted every 2 years and response rates for each interview wave have exceeded 86%. The HRS interviews include detailed participant data: demographics, social and functional characteristics, medical information, caregiving needs and hours of support, and detailed financial data. HRS also links subject's survey data to individual Medicare claims records and the National Death Index. We sampled all HRS decedents identified by a post-death proxy interview between 2006 and 2010 (n=4086). We combined these data with each subject's interview data (on average 2 interviews) from the preceding 5 years.

In order to examine Medicare spending during the last five years of life, we excluded respondents who were less than 70 years of age at time of death (n=851) and those whose date of death fell outside of the study period of January 1, 2005 and December 31, 2010 (n=267). We also excluded individuals without linked Medicare claims data (n=113), who lacked continuous fee-for-service Medicare Parts A and B coverage during the 5 years preceding death (n=103), or who did not provide information regarding entitlement for the full 60 months prior to the date of death (n=75). We were not able to use those with Medicare Part C (i.e., Medicare Advantage) as complete claims data for this group are not available (n=792). Finally, we excluded people for whom there were no core interviews at all in the 5 years preceding death (n=77), no dementia probability estimate (n=100), and those who lived outside of the U.S. (n=6). The final sample included 1702 subjects.

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 individual by the subject's date of death and the 60 months preceding that date. Because HRS surveys are conducted approximately every two years, the sum of months need not 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 utilization reported in the earliest HRS interview, i.e. the time 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 reporting 28 months, then we multiplied the spending and utilization reported in that survey by 24/28 to scale total health care spending to the 60-month period.

Disease cohorts were determined as follows. Subjects were assigned to the dementia group if the probability of dementia at the last available assessment (meaning 24 months prior to death) were greater than 50%. This probability is provided by HRS and reflects an algorithm formulated by HRS investigators and based on multiple cognitive measures; methods are reported elsewhere (9, 14). The reason why we and others use this probabilistic approach is because so few decedents are coded as having died of dementia; most are identified on death records as having died of something else. We conducted sensitivity tests using alternative probability cutoffs for defining the dementia group, specifically probabilities of 70% or greater, and 90% or greater. The remaining subjects in the non-dementia group were

allocated into three groups according to information obtained by the HRS from the National Death Index: Cancer, heart disease, and other primary cause of death.

Health-related out-of-pocket spending is measured every 2 years in the HRS core interviews and again in the post-death interview where 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 Medicare claims for inpatient, outpatient, skilled nursing facility, hospice and home care, as well as durable medical equipment. We collected data on other insurance coverage (Medicaid, private Medigap and long-term care policies, and Veterans Administration coverage) and household wealth from HRS surveys. When respondents don't know the exact amount they spent on a specific item, but instead report a bracket (between $2,000 and $10,000, for example), we use methods in Marshall et al. using HRS data to impute to the individual the mean value of that spending interval(13).

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 nursing home night within the individual'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, 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 upon whether the subject was eligible for Medicaid at that time. This imputation procedure has been described separately(9).

Finally, in order to account for the implicit cost of caregiving beyond that paid by Medicare for home health service and out-of-pocket for hired helpers, we followed a previous study by converting the subjects' reported hours of informal care provided in the month prior to each interview to a five-year total number of hours, multiplied by the state-average costs of home health care services (mean $20/hour, range $16-$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 utilization and spending are therefore derived either from individual Medicare claims data, or from self-reported data in the HRS. Where costs are not explicitly reported, we have used the validated imputation methods described above 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, divided by household wealth, as measured closest to the 5th year prior to death. For sensitivity analysis, we also calculated this ratio for financial wealth, which excludes the equity value of the house. All reported values are adjusted for HRS sampling weights using the most recent weight available for each individual(13).

We considered the patterns of spending associated with socio-demographic factors in two ways. In our primary results, we examined spending across diseases, and across subgroups based on race, marital status, and education. To adjust for the fact that dementia patients tend to be older and with lower educational attainment, we also consider spending measures by disease (dementia and non-dementia cohorts) that are adjusted 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 gamma distribution regression model.

The study was approved by the Mount Sinai School of Medicine Institutional Review Board, the HRS Data Confidentiality Committee, and the CMS Privacy Board. Providers of funding had neither role in the design, conduct, and analysis of this study, nor in the decision to submit the manuscript for publication.

Results

The dementia cohort included 555 subjects with a greater than 50% probability of dementia within 5 years prior to death; the mean probability of dementia among this group was 87%, with 59% of the cohort exhibiting probabilities of dementia in excess of 90%. For remaining subjects (n=1,147), the mean probability of dementia was 12%. The primary cause of death among the non-dementia group included cancer (n=279), heart disease (n=431), or other causes (n=437), as reported in Table 1. The dementia group was older at the time of death (88 years, compared to 82, 85, and 83, respectively), less likely to be married (25%, compared to 44%, 35%, and 39%), and had lower median household wealth at the beginning of the study period ($115,942 compared to $243,168, $203,748, and $220,771). In addition, Medicaid enrollment was significantly higher among the dementia cohort at the start of the study period (21%, compared to 8%, 8% and 13%), as was the *increase* in Medicaid enrollment during the last five years of life (27% for dementia, 12% for cancer, 15% for heart disease, and 15% for other).

The mean adjusted total health care spending in the last five years was $287,038 among those with dementia and $183,001 among other decedents (Table 2). The mean adjusted total Medicare spending in the last 5 years was similar across groups: $86,430 (dementia) and $98,326 (non-dementia); while 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 other group ($4,552, $34,068, and $38,272, respectively). Not only was absolute out-of-pocket spending significantly higher within the dementia group, but out-of-pocket spending as a proportion of total household wealth 5 years prior to death was also substantially higher (median of 32% for dementia and 11% for other diseases). Out-of-pocket spending as a ratio of financial wealth (i.e., excluding housing) was even larger: a median of 242% for dementia and 81% for other diseases. 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 dementia and non-dementia decedents was more pronounced for lower education and minority groups. As

shown in Table 2, among those with dementia and with less than high school education, median out-of-pocket spending accounted for almost half (48%) of wealth 5 years prior to death, compared to 21% for those without dementia. This difference was not as marked among those with attainment of a high school degree or higher education, 24% and 9%, respectively. Similarly, women with dementia and unmarried at the time of death spent 58% of their wealth on out-of-pocket health-related costs, while those without dementia spent 21% and those with a surviving spouse spent 10% or less, regardless of dementia status. An even greater difference was found for dementia decedents who were Black (84%), compared to Black decedents not in the dementia cohort (30%).

Implicit costs of informal care exhibited considerable variation across socio-demographic sub-groups. As noted earlier, average informal care for dementia decedents, $83,022, was more than double the corresponding care for non-dementia decedents, $38,272 (p < 0.001). Figure 1 shows the different patterns by race, education, sex, and marital status of combined out-of-pocket and implicit informal costs faced by families caring for decedents. Black decedents at high risk of dementia experienced much lower levels of out-of-pocket spending ($23,425) than non-Black decedents ($64,819), most likely because of fewer financial resources (Table 2). However, more informal care was provided in Black households ($117,496) compared to non-Black families ($80,038, p < 0.001), so that the sum of combined value of out-of-pocket spending and informal care was nearly identical. A similar pattern of higher out-of-pocket spending, and lower implicit informal care costs, holds as well for high-school graduates compared to those not finishing high school. In both cases, despite finding a marked tradeoff between out-of-pocket spending (higher among non-Blacks and high school graduates) and informal care costs (higher among Blacks and those with lower educational attainment), the total value of these two spending categories were similar across race and education groups.

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

Figure 2 presents estimates of total spending for the dementia and non-dementia cohorts adjusted for age, sex, race, education, marital status and coexisting conditions using a gamma distribution regression model (results presented in the online supplement Table S1). The adjusted overall spending for dementia patients, $279,076, is closer in magnitude to the adjusted spending for the non-dementia cohort, $185,801, with a gap of $93,275 over the entire 5-year period.

Finally, in sensitivity analyses using alternative cutoffs for defining the dementia group, we found that the same pattern of results held whether we limited the dementia group to those with a probability of dementia of 70% or greater (a sample of N = 456 instead of the original 555 sample), or 90% or greater (N = 329). These results are available in the online

supplement Table S2. Sensitivity analyses using the national (instead of state) average prices for nursing home and caregiving costs produced slightly higher cost estimates for all disease groups and categories of spending, although the pattern of results was unchanged.

Discussion

In this paper, we used the nationally-representative HRS cohort to examine the total healthcare spending of beneficiaries who died at age 70 years or older. Over the last 5 years of life, total social costs arising from dementia were more than a quarter-million dollars per person, 57% greater than the social costs associated with death from other diseases. Furthermore, the financial burden for dementia patients was greater than that for individuals with other diseases, both in terms of out-of-pocket spending (in absolute terms and as a percentage of household wealth) and with regard to the implicit cost of informal caregiving. This gap in the financial burden between those at high and low risk of dementia was larger among those who were unmarried, Black, and had less than a high school education – groups most vulnerable to financial risk. Notably, even 5 years prior to death, the dementia group already had markedly lower wealth and a greater percentage enrolled in Medicaid, a proportion that only grew over time. This may be the result of care needs and expenses arising prior to our 5-year look-back period.

Medicare provides nearly universal healthcare coverage for U.S. adults over age 65. However, Medicare does not cover health-related expenses most valuable to those with chronic diseases or a life-limiting illness, such as homecare services and equipment and non-rehabilitative nursing home care. These uninsured needs are greatest among individuals with dementia, a chronic disease characterized by many years of progressive functional decline and supportive care needs. Our findings clearly demonstrate that the predominant determinant of healthcare costs for the dementia group is nursing home and informal care costs, a burden largely borne by individuals and families, particularly among vulnerable subgroups. This leads to over half of all dementia patients who have "spent down" sufficiently to qualify for Medicaid by the time of their death, including three-quarters of those belonging to racial minorities. And despite the presence of Medicaid, among Black and lower education subgroups there is a substitution from out-of-pocket spending into implicit costs of caregiving, putting a larger burden on families(16, 17).

The pioneering study of dementia costs by Hurd et al. used a similarly broad measure of costs associated with caring for those with dementia from the HRS cohort, and found that raising the probability of dementia from 0% to 100% leads to annual additional social costs of between $41,689 and $56,290 per person per year, depending on the imputation method used(9). Our estimated differential costs for the dementia cohort, $93,275 over 5 years, is considerably smaller than their estimate on an annual basis, for two reasons. First, the Hurd et al. measure is a hypothetical assignment that raises probabilities of dementia from 0% to 100%, while we compare cohorts with an average 12% chance of dementia (in the non-dementia cohort) and an average 87% chance (in the dementia cohort). Weighting their figures accordingly would reduce their estimates of dementia costs to between $31,267 and $42,218 annually, 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 non-

dementia cohorts in the last 5 years of life. Because members of our non-dementia cohort are all within 5 years of death, they are likely to be sicker than the non-dementia control group in the Hurd et al. study, leading to smaller difference in costs between the two groups. Our study emphasizes that all households, regardless of disease, face substantial financial risks near the end of life, but that households with dementia patients face even larger risks, particularly with regard to out-of-pocket and implicit costs of caring.

This study is limited in several ways. First, owing to data restrictions, we do not have direct measures of Medicaid or private insurance payments on behalf of the decedents. The methods we have used to impute these payers' expenses are limited to coverage for nursing home care and likely under-represent actual spending. And while we do 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. Similarly, we do not have information on lost wages arising from illness. Few of our decedents are still working 5 years prior to death, but caregivers may be foregoing job opportunities that pay considerably more on an hourly basis than what we impute to them using home health care service rates.

Second, we measure only the probability of dementia and not whether the individual actually had dementia. In theory, death certificate data could be used, but in practice there are relatively few death certificates in which dementia is listed as the primary cause; instead the cause of death reflects the more immediate diagnosis, such as pneumonia. To the extent that we included true dementia patients in the other disease group, the differences we observe between the disease categories are understated. Finally, this paper is not able to measure the value of what is actually purchased with the spending, nor whether there was a concordance between individual preferences or goals and the actual care provided.

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

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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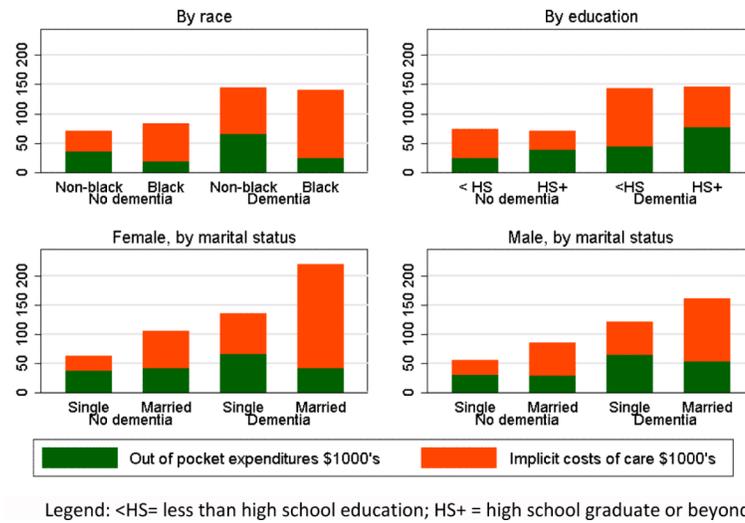
Figure 1. Out-of-Pocket Expenses and Implicit Costs of Informal Care, by Dementia and Demographic Subgroups
Legend: <HS= less than high school education; HS+ = high school graduate or beyond
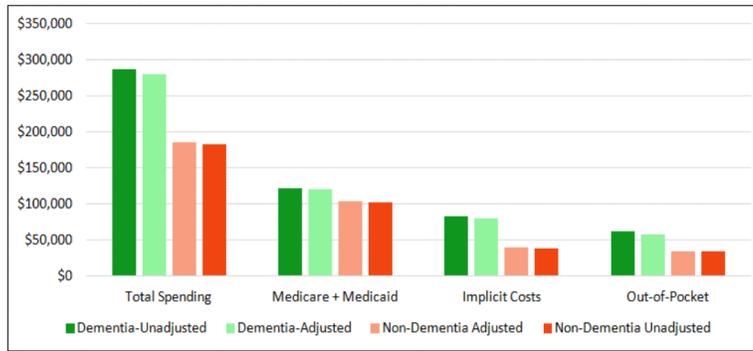
Figure 2. Adjusted and Unadjusted End-of-Life Spending, Dementia and Non-Dementia Cohorts

A

Table 1

Sample characteristics by disease group

	Dementia	Cancer	Heart disease	Other
N	555	279	431	437
Age at death, mean (sd)	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
Education, less than High school, %	46.8[*]	29.4	28.9	34.8
Female, married at death, %	9.0[*]	14.1	11.7	11.2
Female, unmarried at death, %	59.1[*]	40.4	44.3	40.6
Male, married at death, %	16.5[*]	30.1	23.2	28.3
Male, unmarried at death, %	15.4[*]	15.5	20.8	20.0
Medicaid 5yr before death, %	21.1[*]	8.0	7.7	13.3
Medicaid at death, %	48.5[*]	19.8	21.5	28.2
Dementia probability, mean (sd)	0.87[*] (0.16)	0.09 (0.12)	0.13 (0.14)	0.12 (0.14)
Independent in ADLs[+], %	49.8[*]	88.7	85.2	82.6
Self Rated Health fair/poor[+], %	53.9	41.5	43.2	54.7
Currently smokes[+], %	2.8[*]	15.2	8.3	9.2
4 or more self-reported conditions, %	27.9	27.3	28.2	31.1
Total payments, all types, mean	$287,038[*]	$173,383	$175,136	$197,286
Total government payments, mean	$121,776[*]	$102,468	$96,514	$109,813
Medicare payments, mean	$86,430[*]	$101,247	$91,377	$103,786
Out of pocket expenses, mean	$61,522[*]	$28,818	$35,294	$36,073
Imputed informal care costs, mean	$83,022[*]	$39,230	$32,254	$43,988

Dementia group has probability>0.5 of dementia, Cancer, Heart disease and Other disease groups from National Death Index cause of death. ADL=Activities of Daily Living HRS household sample weighting used.

[+] HRS data, on average 5 years before death.

[*] Significantly different (p<0.01) for dementia decedents compared to all other decedents.

Table 2

Spending by Dementia and Other Disease Groups, across Payers, as Proportion of Wealth, and by Subgroups.

	N	Total Social Costs	Medicare & Medicaid	Implicit Costs of Care	Out-of-Pocket Expenditures	Wealth	Out-of-Pocket as % of Wealth
		Mean (Median)	Mean (Median)	Mean (Median)	Mean (Median)	Mean (Median)	Median
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
Non-Black	483	286,241 (257,200)	119,074 (89,906)	80,038 (25,263)	64,819 (40,410)	365,534 (147,412)	31.8
Education, < High school	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 degree 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
Female, married	46	335,573 (297,840)	109,500 (90,473)	177,767 (97,025)	41,381 (26,263)	716,177 (316,907)	7.4
Female, 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
Male, married	85	284,131 (243,766)	110,083 (84,084)	108,524 (54,518)	52,655 (37,547)	518,683 (284,996)	13.8
Male, 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	1,147	183,001 (151,693)	102,878 (81,945)	38,272 (8,566)	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
Non-Black	1,028	180,347 (148,496)	100,684 (80,156)	36,284 (8,115)	35,254 (25,353)	547,770 (247,932)	10.8
Education, < High school	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 degree or higher	768	180,818 (145,130)	100,466 (78,668)	32,948 (6,627)	38,525 (27,364)	657,195 (315,180)	9.4
Female, married	134	214,643 (198,092)	102,282 (92,900)	65,136 (34,029)	40,786 (31,727)	631,137 (348,598)	9.7
Female, not married	473	180,513 (151,693)	106,793 (81,380)	25,126 (6,589)	37,182 (25,003)	308,272 (128,623)	21.1
Male, married	321	197,552 (153,785)	109,862 (82,778)	56,450 (14,496)	28,576 (22,387)	743,480 (370,635)	6.4
Male, not married	219	148,439 (122,327)	85,038 (62,411)	24,918 (4,188)	30,678 (22,432)	598,714 (263,937)	10.1

Out-of-Pocket as % of Wealth is calculated for each subject, then reported as the groups' median ratio. Spending is adjusted to 2010$ for inflation and discounted to 5 years before death. HRS weights are used. Imputed 3rd party payments for nursing home costs included in total social costs but not listed here separately.