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DATAWATCH

Financial Hardships Of Medicare Beneficiaries With Serious Illness

In a national survey, seriously ill Medicare beneficiaries described financial hardships resulting from their illness—despite high beneficiary satisfaction with Medicare overall and the fact that many have supplemental insurance. About half reported a serious problem paying medical bills, with prescription drugs proving most onerous.

People with serious health conditions bear a disproportionate burden of health care costs. In a national survey we found that seriously ill Medicare beneficiaries experienced considerable financial distress as a consequence of the illness (exhibit 1). Fifty-three percent of the beneficiaries reported having a serious problem paying a medical bill of any kind. Prescription drugs posed the greatest hardship (30 percent), followed by hospital bills (25 percent).

Medicare is considered relatively good insurance: Research that examined access and affordability for people just under and just over age sixty-five has found meaningful decreases in out-of-pocket spending after reaching age sixty-five and fewer reports of cost-related barriers to care.[1,2] In a previous survey of US adults, Medicare beneficiaries were among those most satisfied with how the health care system is working.[3] But traditional Medicare has well-known gaps in financial protection—notably, the lack of a cap on out-of-pocket spending.[4] To mitigate this exposure, 90 percent of Medicare beneficiaries have supplemental (Medigap) insurance, are in Medicare Advantage, or are dually covered by Medicaid.[5]

The perception that Medicare works well for most beneficiaries obscures the financial exposure that is concentrated among the seriously ill. According to the National Academy of Medicine, 5 percent of patients account for nearly half of all national health care spending, and 55 percent of high-need patients are ages sixty-five and older.[6] High-need Medicare beneficiaries may be especially vulnerable, since patients in the top 5 percent of spending account for more than half of out-of-pocket spending.[7] Health care cost growth outpaces inflation, so patients' spending can increase over time even if their consumption re-

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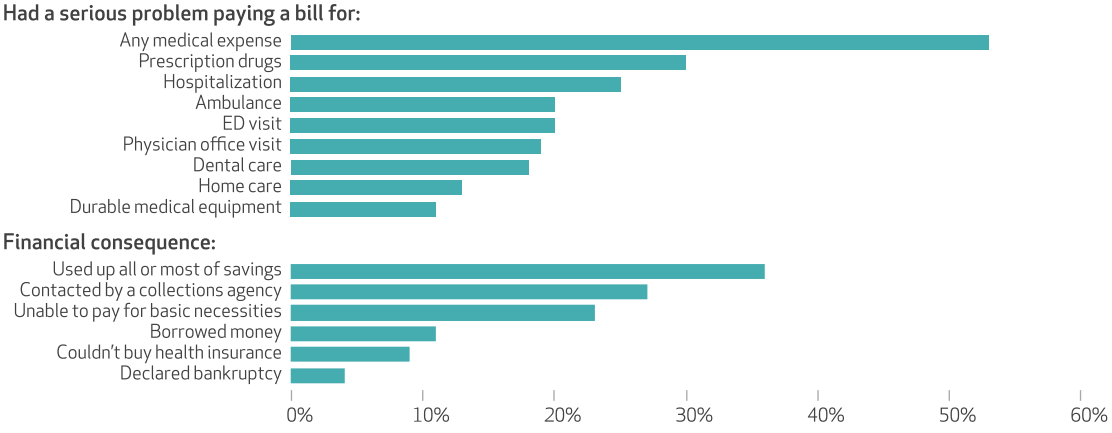
EXHIBIT 1

Percent of Medicare beneficiaries who reported financial consequences of serious illness in 2018



SOURCE Authors' analysis of data for 2018 from the Commonwealth Fund, *New York Times*, and Harvard T. H. Chan School of Public Health survey of people with serious illness. **NOTES** Basic necessities include food, heat, and housing. "Borrowed money" includes taking out a loan or second mortgage. ED is emergency department.

mains fixed.[4] Additionally, improvements in technology may lead patients to consume care that is more effective but also more expensive, such as high-cost pharmaceuticals.[8]

EXHIBIT 2

Sample characteristics of seriously ill Medicare beneficiaries, by dual enrollment status, 2018

	All (*N* = 742)	Not dually enrolled (*n* = 589)	Dually enrolled (*n* = 153)
Sex			
Male	42%	45%	36%
Female	58	55	64
Age (years)			
Less than 65	38	31	57****
65 or older	62	69	42****
Race/ethnicity			
White	70	76	54****
Black	11	8	17**
Hispanic	10	8	18***
Other	9	7	12
Household income			
Less than $15,000	26	19	44****
$15,000 to <$50,000	45	46	40
$50,000 to <$100,000	14	17	7****
$100,000 or more	7	9	1****
Condition			
Diabetes requiring insulin	23	21	30
Heart disease, heart failure, or MI	34	35	31
Cancer (other than skin cancer)	22	21	22
Stroke	18	17	21
Anxiety or depression	28	27	32
Opioid addiction	2	1	4
Serious injury or accident	24	23	26
Composite "Big 4"[a]	66	64	72
No. of doctors seen in past 3 years			
Fewer than 5	36	37	32
5–9	53	52	57
10 or more	10	10	10
No. of overnight hospital stays in past 3 years			
2	39	41	35
3	19	19	20
4	11	11	9
5	7	6	8
More than 5	24	23	28
No. of prescription drugs			
None	2	1	3
1–4	21	21	22
5–9	45	45	43
10 or more	29	29	29

SOURCE Authors' analysis of data for 2018 from the Commonwealth Fund, *New York Times*, and Harvard T. H. Chan School of Public Health survey of people with serious illness. **NOTES** Dually enrolled respondents were those who reported having both Medicare and Medicaid coverage. The percentages shown are of the US population of seriously ill adults with Medicare coverage, estimated with survey weights to adjust for the unequal probability of sampling. Percentages in a category might not sum to 100 percent because of rounding and responses of "don't know" or refusals to answer that were included in the total but not shown. Significance indicates difference (measured by *t*-tests) between beneficiaries who were and were not dually enrolled. [a]Composite measure of self-reports of having at least one of four prevalent, high-morbidity illnesses: diabetes requiring insulin; heart disease, heart failure, or myocardial infarction (MI); cancer (other than skin cancer); and stroke. **$p < 0.05$ ***$p < 0.01$ ****$p < 0.001$

There is no consensus definition of *seriously ill patients*, but prior studies of Medicare populations with high-need, high-cost conditions such as dementia or cancer found that these patients face high out-of-pocket spending.[8–10] One analysis of Medicare expenditures found that over a quarter of beneficiaries spend more than 20 percent of their income on premiums and medical costs.[11]

This article reports seriously ill Medicare beneficiaries' assessments of the cost of their care on themselves and their family and friends.

Study Data And Methods

We analyzed survey data from an original, nationally representative, probability-based sample of seriously ill adults covered under Medicare or their proxies. This work is part of a larger study conducted by the Harvard T. H. Chan School of Public Health, the *New York Times*, and the Commonwealth Fund.[12] Survey topics that addressed the financial consequences of serious illness included the adequacy of insurance coverage, barriers to care, effects on overall financial stability, care at home from family members or friends, and the material consequences of caregiving on family members or friends. Prior reports have documented the experience of the seriously ill overall,[12,13] but this is the first analysis of Medicare beneficiaries.

We defined respondents as seriously ill if they reported having a serious illness or condition that, over the past three years, had required two or more hospital stays and visits to three or more physicians. We defined respondents as Medicare beneficiaries if they were ages sixty-five and older and reported having Medicare coverage, or if they were younger than age sixty-five and reported having Medicare coverage and being disabled. We defined people as dually enrolled if they reported having both Medicare and Medicaid coverage. Typically the dually enrolled population is both elderly and low-income. We described beneficiaries with Medicare but not Medicaid as "non–dually enrolled."

The survey was conducted by phone in the period July 6–August 18, 2018. We screened the general population through random-digit dialing, selecting respondents who met our criteria for serious illness. Among all adult respondents, 11.9 percent were identified as seriously ill (19.3 percent among those age sixty-five and older).

This study was determined to be exempt by the Office of Human Research Administration of the Harvard T. H. Chan School of Public Health.

We calculated weighted descriptive statistics for the overall sample and for those dually and

not dually enrolled in Medicare and Medicaid. We used t-tests to compare the latter two groups, considering p values of $p < 0.05$ to be significant. (See online appendix A1 for details on our methods.)[14]

Our study had several limitations. First, self-reported data are subject to recall bias and other human error.

Second, our survey had a response rate of 21 percent. While not ideal, the response rate was consistent with those of similar surveys of this type. Prior research suggests that surveys based on probability samples and weighted using the US census, as this survey was, yield accurate estimates in most cases, when compared with both objective data and surveys with higher response rates.[15,16] Evidence suggests that even with lower response rates, bias is avoidable as long as the sample is representative of the overall study population.[17]

Third, we benchmarked our results against other data sources. Differences in sampling and questions precluded direct comparisons, but our findings were broadly consistent with those of larger surveys and with objective measures. (See appendix A3 for details.)[14]

Fourth, as stated above, there is no consensus definition of *seriously ill patients*. Thus, the application of these findings to other high-need, high-cost groups should be done cautiously.

Fifth, the survey instrument was not specifically designed for the Medicare population, and financial protection was one of a range of topics covered.

Sixth, we asked about Medicare, Medicaid, and dual coverage in detail, but there could be error in self-reports. We did not ask granular questions about insurance coverage—that is, we did not distinguish between traditional Medicare and Medicare Advantage, nor did we ask whether people had Medigap supplemental coverage.

Finally, the statistical power of some subgroup comparisons may have been limited by the available sample size.

Study Results

Our sample included 742 Medicare beneficiaries, 607 of whom responded directly to the survey; proxies (for example, spouses) responded for the remaining 135 beneficiaries. The response rate was 21 percent (margin of error: plus or minus 4.6 percent). Examining the sample's characteristics, we found that dual enrollees were significantly younger, less likely to be white, more likely to be black or Hispanic, and more likely to be low income compared to beneficiaries who were not dually enrolled (exhibit 2).

Exhibit 3 describes the financial consequences experienced by Medicare beneficiaries with serious illness. We did not establish a standard for financial hardship, since we were interested in how respondents characterized the financial impact of serious illness in their lives. Among all respondents, 53 percent reported having had a serious problem paying a medical bill of any kind. Prescription drugs posed the greatest hardship (30 percent), followed by hospital (25 percent), ambulance (20 percent), and emergency department (20 percent) bills. Beneficiaries reported extensive financial hardships as a consequence of the costs of their serious illness, including using up all or most of their savings (36 percent); being contacted by a collections agency (27 percent); and being unable to pay for basic necessities, such as food, heat, and housing (23 percent). Other consequences included emotional or psychological distress (45 percent) and problems caring for a dependent (24 percent). There were no significant differences between beneficiaries who were and were not dually enrolled.

EXHIBIT 3

Financial and other consequences of serious illness for Medicare beneficiaries, by dual enrollment status, 2018

	All	Not dually enrolled	Dually enrolled
Had a serious problem paying a bill for:[a]			
Any medical expense	53%	52%	57%
Prescription drugs	30	29	34
Hospitalization	25	27	19
Ambulance	20	21	19
Emergency department visit	20	19	22
Physician office visit	19	20	17
Dental care	18	18	20
Home care	13	14	10
Durable medical equipment	11	9	14
Other financial consequences[b]			
Used up all or most of savings	36	33	45
Contacted by a collections agency	27	29	20
Unable to pay for basic necessities	23	21	30
Borrowed money	11	11	11
Couldn't buy health insurance	9	10	5
Declared bankruptcy	4	4	6
Other consequences[b]			
Emotional or psychological distress	45	42	55
Had a problem caring for a dependent	24	25	20

SOURCE Authors' analysis of data for 2018 from the Commonwealth Fund, *New York Times*, and Harvard T. H. Chan School of Public Health survey of people with serious illness. **NOTES** Dually enrolled respondents were those who reported having both Medicare and Medicaid coverage. The percentages shown are of the US population of seriously ill adults with Medicare coverage, estimated with survey weights to adjust for the unequal probability of sampling. Percentages in a category might not sum to 100 percent because of rounding and responses of "don't know" or refusals to answer that were included in the total but not shown. Basic necessities include food, heat, and housing. "Borrowed money" includes taking out a loan or second mortgage. [a]Question asked of a random half-sample ($n = 364$). [b]Questions asked of a random half-sample ($n = 378$).

When asked how much their overall medical costs had burdened their family, 25 percent of the seriously ill said that costs were a major burden, and 30 percent said that they were a minor burden (exhibit 4). When asked about getting help in recent years, 60 percent said that family members and friends helped a lot, 25 percent said that they helped a little, and 14 percent said that they provided no help. Family members and friends experienced considerable strain as a consequence of providing help, including financial problems, lowered income, and lost or changed jobs or reduced hours. Twenty-nine percent of respondents said that there was a time when they did not get outside help because of cost.

When navigating information about costs and billing, only 46 percent of the seriously ill felt adequately informed by health professionals about what costs their insurance would cover (exhibit 5). Dually enrolled beneficiaries were more likely than others to have a problem understanding what insurance would cover for hospital stays but less likely to receive a bill after their last hospital stay for services not fully covered.

Discussion

In contrast with studies that estimated an empirical measure of hardship based on a dollar amount or share of income,[8,9,11] this study documented seriously ill people's own assessment of financial strain on themselves and their family and friends. Respondents described substantial and pervasive burdens in coping with the costs of serious illness.

Given the evidence of Medicare's popularity among its beneficiaries and its comparatively good financial protection relative to commercial insurance, the extent of financial strain among seriously ill Medicare beneficiaries was notable and should invite further investigation.[2,3] While we expected our sample to include people with Medicare Advantage and Medigap, given the prevalence of these products, our data did not reliably capture this information. Distinguishing financial burdens across types of Medicare coverage is an important area for future research.[5] We compared beneficiaries who were and were not dually enrolled, since dual enrollees were a group in our sample that we knew had

EXHIBIT 4

Consequences for family members and friends of seriously ill Medicare beneficiaries, by dual enrollment status, 2018

	All	Not dually enrolled	Dually enrolled
How much of a burden on your family have costs of your overall medical care been?[a]			
Major burden	25%	25%	26%
Minor burden	30	32	25
Not a burden	44	43	48
In recent years, how much help did family and friends provide to help deal with your health or medical condition?[a]			
A lot	60	60	60
A little	25	26	24
None at all	14	13	16
Was it a problem for family or friends to provide this help?[b]			
Yes	38	36	43
What problems did family or friends experience?[b]			
Emotional stress	33	31	39
Physical strain	25	23	31
Emotional or psychological problems	24	22	29
Financial problems	23	22	25
Lowered income	22	21	25
Lost or changed jobs or reduced hours	17	16	18
Health problems	17	14	24
Conflict among family members	17	13	28
Was there a time you didn't get outside help because of cost?[a]			
Yes	29	30	27

SOURCE Authors' analysis of data for 2018 from the Commonwealth Fund, New York Times, and Harvard T. H. Chan School of Public Health survey of people with serious illness. **NOTES** Dually enrolled respondents were those who reported having both Medicare and Medicaid coverage. The percentages shown are of the US population of seriously ill adults with Medicare coverage, estimated with survey weights to adjust for the unequal probability of sampling. Percentages in a category might not sum to 100 percent because of rounding and responses of "don't know" or refusals to answer that were included in the total but not shown. [a]Questions asked of a random half-sample ($n = 378$). [b]Portion of half-sample receiving help from family members or friends ($n = 326$).

EXHIBIT 5

Seriously ill Medicare beneficiaries' experiences with information about costs and billing, by dual enrollment status, 2018

	All	Not dually enrolled	Dually enrolled
Felt adequately informed by health professionals about costs insurance covers[a]	46%	44%	50%
Main doctor discussed cost of care[a]	27	23	37
Physician office visits			
Had problem understanding what insurance covers[b]	27	27	18
Had problem understanding a bill[b]	19	20	18
Hospital stays			
Had problem understanding what insurance covers[c]	21	18	33**
After last stay, received a bill for services not fully covered by insurance[d]	38	42	24***

SOURCE Authors' analysis of data for 2018 from the Commonwealth Fund, *New York Times*, and Harvard T. H. Chan School of Public Health survey of people with serious illness. **NOTES** Dually enrolled respondents were those who reported having both Medicare and Medicaid coverage. The percentages shown are of the US population of seriously ill adults with Medicare coverage, estimated with survey weights to adjust for the unequal probability of sampling. Percentages in a category might not sum to 100 percent because of rounding and responses of "don't know" or refusals to answer that were included in the total but not shown. Significance indicates difference (measured by *t*-tests) between beneficiaries who were and were not dually enrolled. [a]Questions asked of a random half-sample ($n = 364$). [b]Questions asked of a random half-sample ($n = 311$). [c]Question asked of a random half-sample ($n = 371$). [d]Question asked of a random half-sample ($n = 389$). $^{**}p < 0.05$ $^{***}p < 0.01$

secondary coverage (via Medicaid). However, while they have the added protection of Medicaid, they are more likely to be poor and disabled. For the seriously ill, gaps in Medicare's financial protection may persist even with secondary insurance.

Paying for prescription drugs was the most commonly reported bill problem. The number of prescriptions taken, high cost of individual prescriptions, and benefit design (for example, doughnut hole, formularies, and cost sharing) are all potential drivers of out-of-pocket spending. While this study was not designed to evaluate the mechanisms underlying prescription drug costs, our results underscore the salience of high prescription drug costs from the patient's perspective.

High-need, high-cost patients are often associated with acute or end-of-life care, but many people with serious illness are living in the community. This study largely described people living at home: Over 80 percent of the seriously ill subjects participated in the telephone survey themselves. However, the majority needed help at home, at considerable cost to their family and friends.

Conclusion

Medicare insurance is broadly popular, but seriously ill beneficiaries who most need financial protection report widespread problems affording care and financial instability. ■

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