

# Out-of-Pocket Spending and Financial Burden Among Medicare Beneficiaries With Cancer

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**IMPORTANCE** Medicare beneficiaries with cancer are at risk for financial hardship given increasingly expensive cancer care and significant cost sharing by beneficiaries.

**OBJECTIVES** To measure out-of-pocket (OOP) costs incurred by Medicare beneficiaries with cancer and identify which factors and services contribute to high OOP costs.

**DESIGN, SETTING, AND PARTICIPANTS** We prospectively collected survey data from 18 166 community-dwelling Medicare beneficiaries, including 1409 individuals who were diagnosed with cancer during the study period, who participated in the January 1, 2002, to December 31, 2012, waves of the Health and Retirement Study, a nationally representative panel study of US residents older than 50 years. Data analysis was performed from July 1, 2014, to June 30, 2015.

**MAIN OUTCOMES AND MEASURES** Out-of-pocket medical spending and financial burden (OOP expenditures divided by total household income).

**RESULTS** Among the 1409 participants (median age, 73 years [interquartile range, 69-79 years]; 46.4% female and 53.6% male) diagnosed with cancer during the study period, the type of supplementary insurance was significantly associated with mean annual OOP costs incurred after a cancer diagnosis (\$2116 among those insured by Medicaid, \$2367 among those insured by the Veterans Health Administration, \$5976 among those insured by a Medicare health maintenance organization, \$5492 among those with employer-sponsored insurance, \$5670 among those with Medigap insurance coverage, and \$8115 among those insured by traditional fee-for-service Medicare but without supplemental insurance coverage). A new diagnosis of cancer or common chronic noncancer condition was associated with increased odds of incurring costs in the highest decile of OOP expenditures (cancer: adjusted odds ratio, 1.86; 95% CI, 1.55-2.23;  $P < .001$ ; chronic noncancer condition: adjusted odds ratio, 1.82; 95% CI, 1.69-1.97;  $P < .001$ ). Beneficiaries with a new cancer diagnosis and Medicare alone incurred OOP expenditures that were a mean of 23.7% of their household income; 10% of these beneficiaries incurred OOP expenditures that were 63.1% of their household income. Among the 10% of beneficiaries with cancer who incurred the highest OOP costs, hospitalization contributed to 41.6% of total OOP costs.

**CONCLUSIONS AND RELEVANCE** Medicare beneficiaries without supplemental insurance incur significant OOP costs following a diagnosis of cancer. Costs associated with hospitalization may be a primary contributor to these high OOP costs. Medicare reform proposals that restructure the benefit design for hospital-based services and incorporate an OOP maximum may help alleviate financial burden, as can interventions that reduce hospitalization in this population.

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Among the 5 health conditions that contribute most to health care costs in the United States, per-person direct medical expenditures on cancer are the highest.<sup>1</sup> Moreover, annual direct medical expenditures on cancer are projected to increase by nearly 40% from 2010 to 2020, largely owing to a combination of changing demographics, increased use of services, and expensive new treatments.<sup>2</sup> As most new cancers and cancer-associated deaths occur in adults older than 65 years, much of this cost burden will be borne by Medicare, the federal health insurance program for the elderly and disabled.<sup>3</sup>

However, traditional Medicare also requires considerable cost sharing from its beneficiaries and does not include an out-of-pocket (OOP) maximum.<sup>4</sup> Although supplemental coverage through Medigap, employer-sponsored insurance, or Medicaid can minimize OOP costs, considerable heterogeneity exists in the design of benefits, placing seniors at variable financial risk. Medicare beneficiaries who obtain their benefits through a health maintenance organization (HMO) face similar variation in the design of benefits.<sup>4</sup> Moreover, more than 4 million Medicare beneficiaries lack supplemental insurance altogether and may be particularly vulnerable following a major diagnosis, such as cancer.<sup>4</sup> Indeed, reports have increasingly documented the adverse consequences of cancer on patients' financial well-being, including depleted savings and even bankruptcy.<sup>5-7</sup> Financial distress may also discourage use of effective services, including poor adherence to key anticancer therapies.<sup>6-13</sup> Protecting patients against the "financial toxicity" of cancer has therefore become a central objective of the oncology community.<sup>14-19</sup>

Ensuring the financial security of elderly patients with cancer requires an understanding of which patients experience high OOP costs and what services contribute to these costs. Prior work on this subject has been limited by older data and exclusion of Medicare beneficiaries who receive their benefits through an HMO, which now represents 30% of Medicare beneficiaries.<sup>20-22</sup> In addition, there is limited information on the service categories that contribute to high OOP costs, and existing comparisons of OOP costs across disease types have included patients in a nursing home, whose high long-term care costs dwarf other cost categories.<sup>23</sup>

We address these gaps by characterizing the distribution of OOP costs incurred by a nationally representative cohort of community-dwelling Medicare beneficiaries. We also examine the variation in OOP costs based on types of supplemental insurance. Finally, we explore which services were primarily responsible for imposing significant financial burden on the beneficiaries who incurred the highest OOP costs.

## Methods

### Study Population

We analyzed survey data from the July 1, 2002, to December 31, 2012, waves of the Health and Retirement Study (HRS), a nationally representative, longitudinal panel study of US residents older than 50 years.<sup>24</sup> The HRS is designed to collect detailed health, demographic, and financial information

### Key Points

**Questions** What are the out-of-pocket (OOP) costs incurred by Medicare beneficiaries with cancer, and what factors and services drive these high OOP costs?

**Findings** In this nationally representative panel study, Medicare beneficiaries with a new cancer diagnosis were vulnerable to high OOP costs depending on their supplemental insurance: beneficiaries without supplemental insurance incurred OOP expenditures that were a mean of 23.7% of their household income, with 10% incurring OOP costs that were 63.1% of their household income. Hospitalizations were a primary driver of these high OOP costs.

**Meaning** Elderly patients with cancer need improved protection against costly hospitalizations.

from its participants and includes data on their OOP medical expenditures.<sup>25</sup> Approximately 20 000 participants are interviewed biennially, with response rates of more than 85% during the study period.<sup>26</sup> Oral informed consent is obtained from participants as part of the HRS process. Our study was approved by the Johns Hopkins Hospital Institutional Review Board.

The population included community-dwelling HRS participants older than 65 years who were enrolled in either fee-for-service Medicare or obtained Medicare benefits through an HMO. Nursing home residents were excluded given their distinct patterns of resource use compared with community-dwelling Medicare beneficiaries.<sup>27</sup> Participants with a new diagnosis of cancer were identified based on their first affirmative response to the following question: "Has a doctor ever told you that you have cancer or a malignant tumor, excluding minor skin cancer?" The reported date of diagnosis was also cross-referenced with survey administration dates to confirm the interval in which a cancer diagnosis was made. Subsequent surveys from patients newly diagnosed with cancer were excluded from the analysis except for the HRS exit interview, which was used to analyze the cost of end-of-life care. In addition, we used similar survey items to identify patients who were diagnosed with 1 of the 5 most common nonaccidental causes of mortality in the United States (ie, heart disease, lung disease, stroke, dementia, and type 1 or 2 diabetes).<sup>28</sup>

### OOP Expenditures

Our primary outcome of interest was the level of OOP expenditures incurred by HRS participants between survey administrations. Since 2002, the HRS has collected detailed data on OOP expenditures using the following cost categories: inpatient hospitalization, nursing home, clinic visits with a physician, dental care, outpatient surgery, prescription drugs, home health care, and other health services. More important, the HRS did not provide respondents with explicit instructions on the assignment to a specific cost category of radiation services, chemotherapy, or oral targeted anticancer agents.

For each cost category other than prescription drugs, HRS participants are asked, "About how much did you pay out of pocket for XX [since the last interview or in the last 2 years]?"

For prescription drugs, participants are asked about OOP expenditures in the month prior to the interview. Median time between surveys was 2.0 years (interquartile range, 1.8-2.4 years). Out-of-pocket expenditures were normalized to an annual scale, and values were adjusted to 2012 dollars.<sup>29</sup>

The HRS uses an innovative method of random entry bracketing, in which nonrespondents sequentially refine an estimated range of OOP expenditures (eAppendix in the [Supplement](#)). For participants reporting expenditures within a bracketed range, exact OOP expenditure values were imputed using a method developed by the RAND Corporation, as described elsewhere.<sup>30</sup> Although 12 668 of the 61 339 responses (20.7%) that were provided with respect to OOP expenditures were not exact amounts, the bracketing approach minimized complete nonresponse to any item to less than 5%.<sup>31</sup>

### Income, Wealth, and Supplemental Insurance

Indexing OOP expenditures to financial well-being may allow for a better estimate of financial distress. We calculated financial burden as OOP expenditures divided by total household income.<sup>32,33</sup> The HRS collects comprehensive data on household income and household wealth (eAppendix in the [Supplement](#)). Components of household income and wealth were summed for both the participant and spouse, if present. All income and wealth measures are reported in 2012 dollars.<sup>29</sup>

To examine the association between participants' OOP expenditures and insurance arrangements, participants were classified into 1 of 6 mutually exclusive insurance categories, which included 5 types of supplemental insurance arrangements for patients enrolled in fee-for-service Medicare, as well as a category for patients in a Medicare HMO. In order of an expectation of increased cost sharing, these insurance categories included Medicaid; Veterans Health Administration; Medicare HMO; employer-sponsored insurance, including retiree and spousal coverage; Medigap; and none.<sup>34</sup> A simplified classification schema was also used in which the Medicaid and Veterans Health Administration categories were combined into the category of public supplemental insurance, and the employer-sponsored and Medigap categories were consolidated into private supplemental insurance.

### Statistical Analysis

Data analysis was performed from July 1, 2014, to June 30, 2015. Baseline sociodemographic and health-associated characteristics were compared between patients with and without cancer using a 2-sample *t* test and  $\chi^2$  test for continuous and categorical variables, respectively. A multivariable generalized linear model was constructed to assess mean OOP expenditures using a log link function and gamma family distribution. Multivariable quantile regression was performed to assess the median and 90th percentile of OOP expenditures. Multivariable logistic regression was also performed to determine which factors were associated with incurring costs in the highest decile of OOP expenditures. Models were adjusted for age, sex, race/ethnicity, educational level, marital status, geographic region, self-reported health, comorbidity, smoking status, wealth quartile, and type of supplemental insurance. In addition, we accounted for potential

correlation within participant responses from multiple survey waves by clustering standard errors by participants' unique identification number.

Out-of-pocket expenditures for HRS participants with cancer were compared with OOP expenditures among participants with other common disease types that contribute to mortality in the United States.<sup>28</sup> Comparisons were repeated within patient subsets that were defined by type of supplemental insurance. A similar method was used for analyzing financial burden. In addition, the relative contribution of each OOP cost category to total OOP costs was examined.

The HRS selects its participants using a complex, multi-stage, area probability sampling design.<sup>35</sup> Because the HRS oversamples African Americans and Hispanics, sampling weights are created such that the weighted HRS sample is representative of community-dwelling US households. We accounted for the complex sampling design by applying respondent-level sampling weights in all calculations.

Throughout the analysis, 2-sided significance testing was used, and *P* = .05 was considered statistically significant. All statistical analyses were performed with Stata/IC software, version 10.0 (StataCorp).

## Results

A total of 18 166 community-dwelling US residents older than 65 years participated in the HRS between 2002 and 2012 and were enrolled in fee-for-service Medicare or received Medicare benefits through an HMO. Participants completed a median of 3 survey waves (range, 1-6) and produced 61 339 observations.

During the study period, 1409 participants (7.8%) were newly diagnosed with cancer ([Table 1](#)). Median time from cancer diagnosis to survey completion was 1.2 years (interquartile range, 0.8-1.6 years). Compared with patients who did not have cancer, HRS participants who were newly diagnosed with cancer were more likely to be male (53.6% vs 43.4%; *P* < .001), white (90.5% vs 87.9%; *P* = .001), non-Hispanic (96.1% vs 93.2%; *P* < .001), married (63.2% vs 59.2%; *P* = .01), and report higher self-assessed health status (good to excellent health, 76.2% vs 61.4%; *P* < .001) despite more frequently indicating a history of heart (32.8% vs 30.1%; *P* = .05) or lung (14.9% vs 10.9%; *P* < .001) disease. Although patients with cancer generally belonged to higher wealth (third and fourth quartiles, 57.0% vs 48.8%; *P* = .001) and income quartiles (third and fourth quartiles, 53.6% vs 49.1%; *P* = .002), substantial heterogeneity in wealth and income was present. Patients with cancer who were in lower wealth and income quartiles more commonly had Medicaid coverage or lacked supplemental insurance and less commonly had employer-sponsored or Medigap supplemental insurance (*P* < .001 for all; eTable 1 in the [Supplement](#)) compared with patients with cancer who were in higher wealth and income quartiles.

Mean annual OOP expenditures was \$3737 and financial burden was 11.4% for all HRS participants. The distributions of OOP expenditures and financial burden were right-skewed: at the 90th percentile, annual OOP expenditures were \$8078 and financial burden was 29.6%. A new diagnosis of

Table 1. Participant Characteristics

Characteristic <sup>a</sup>	Value <sup>b</sup>		P Value
	No Cancer (n = 16 757)	Newly Diagnosed Cancer (n = 1409)	
Age, median (IQR), y	73 (69-80)	73 (69-79)	.14
Female	9484 (56.6)	654 (46.4)	<.001
Race			
White	14 730 (87.9)	1275 (90.5)	.001
Black	1441 (8.6)	110 (7.8)	
Other	586 (3.5)	24 (1.7)	
Hispanic ethnicity	1139 (6.8)	55 (3.9)	<.001
Marital status			
Married	9920 (59.2)	891 (63.3)	.01
Separated or divorced	1659 (9.9)	154 (10.9)	
Widowed	4608 (27.5)	333 (23.7)	
Single	570 (3.4)	31 (2.2)	
Self-reported health			
Poor	1509 (9.0)	52 (3.7)	<.001
Fair	4951 (29.5)	285 (20.2)	
Good	5588 (33.3)	440 (31.3)	
Very good	3402 (20.3)	363 (25.8)	
Excellent	1307 (7.8)	269 (19.1)	
Comorbidity			
Lung disease	1827 (10.9)	210 (14.9)	<.001
Heart disease	5044 (30.1)	462 (32.8)	.05
Wealth quartile <sup>c</sup>			
First	4323 (25.8)	245 (17.4)	.001
Second	4256 (25.4)	361 (25.6)	
Third	4140 (24.7)	382 (27.1)	
Fourth	4038 (24.1)	421 (29.8)	
Income quartile <sup>d</sup>			
First	4290 (25.6)	262 (18.6)	.002
Second	4240 (25.3)	392 (27.8)	
Third	4138 (24.7)	369 (26.2)	
Fourth	4089 (24.4)	386 (27.4)	
Supplemental insurance			
Medicaid	1441 (8.6)	111 (7.9)	.004
Veterans Health Administration	1005 (6.0)	116 (8.2)	
Medicare HMO	3301 (19.7)	251 (17.8)	
Employer-sponsored	4709 (28.1)	391 (27.8)	
Medigap	3754 (22.4)	353 (25.1)	
None	2547 (15.2)	187 (13.3)	

Abbreviations: IQR, interquartile range; HMO, health maintenance organization.

<sup>a</sup> Some variables in the multivariable model are not listed here owing to table length, namely, geographic region, educational level, multiple comorbidities (hypertension, stroke, arthritis, psychiatric illness, and type 1 or 2 diabetes), and smoking status. No differences were seen in these variables between participants with and without cancer.

<sup>b</sup> Data are presented as number (percentage) of participants unless otherwise indicated.

<sup>c</sup> Wealth quartiles: first, <\$89 581; second, \$89 582-\$256 293; third, \$256 294-\$638 926; fourth, >\$638 926.

<sup>d</sup> Income quartiles: first, <\$22 380; second, \$22 381-\$37 198; third, \$37 199-\$64 579; fourth, >\$64 579.

cancer or common chronic noncancer condition was associated with increased odds of incurring costs in the highest decile of OOP expenditures (cancer: adjusted odds ratio [AOR], 1.86; 95% CI, 1.55-2.23; *P* < .001; chronic noncancer condition: AOR, 1.82; 95% CI, 1.69-1.97; *P* < .001) (Table 2) compared with other HRS participants. Likewise, HRS participants with private supplemental insurance, without supplemental insurance, or who obtained Medicare benefits through an HMO all had increased odds of incurring costs that were in the highest decile of OOP expenditures compared with participants with Medicaid or Veterans Health Administration coverage (Medicare HMO: AOR, 1.80; 95% CI, 1.55-2.08; *P* < .001; private supplemental: AOR, 2.38; 95% CI, 2.09-2.71; *P* < .001; and none: AOR,

2.86; 95% CI, 2.48-3.29; *P* < .001). Similar associations were seen with financial burden (Table 2).

Adjusted OOP expenditures for HRS participants newly diagnosed with cancer were compared with adjusted OOP expenditures for HRS participants newly diagnosed with common chronic noncancer conditions that contribute to mortality (eTable 2 in the Supplement). Although mean OOP expenditures were similar between disease types for the overall cohort, mean OOP expenditures in participants lacking supplemental insurance were significantly higher for cancer than for other disease types.

All participants newly diagnosed with cancer experienced significantly higher mean annual OOP expenditures

**Table 2. Variables Associated With High Out-of-Pocket Expenditures and Financial Burden**

Variable	Adjusted Odds Ratio (95% CI)			
	High Out-of-Pocket Expenditures <sup>a</sup>	P Value	High Financial Burden	P Value
Age, y [reference, <70]				
70-80	0.98 (0.90-1.06)	.55	1.11 (1.02-1.21)	.02
>80	1.16 (1.05-1.29)	.004	1.41 (1.27-1.56)	<.001
Sex [reference, male]				
Female	1.12 (1.04-1.21)	.004	1.30 (1.20-1.42)	<.001
Race [reference, white]				
Black	0.92 (0.81-1.03)	.15	1.25 (1.12-1.39)	<.001
Other	0.78 (0.61-1.01)	.06	0.90 (0.72-1.11)	.33
Hispanic ethnicity [reference, no]				
Yes	0.81 (0.68-0.96)	.02	1.19 (1.02-1.37)	.02
Educational level [reference, less than high school]				
High school graduate	1.00 (0.90-1.11)	.99	0.74 (0.68-0.82)	<.001
Some college	1.17 (1.03-1.32)	.01	0.70 (0.62-0.79)	<.001
College graduate	1.34 (1.18-1.52)	<.001	0.58 (0.51-0.65)	<.001
Marital status [reference, married]				
Separated or divorced	0.86 (0.75-1.00)	.05	2.51 (2.23-2.84)	<.001
Widowed	0.90 (0.82-0.98)	.02	2.20 (2.02-2.40)	<.001
Single	0.77 (0.59-1.00)	.05	2.35 (1.87-2.96)	<.001
Wealth quartile [reference, first] <sup>b</sup>				
Second	0.96 (0.87-1.07)	.49	NA	NA
Third	0.98 (0.88-1.10)	.79	NA	NA
Fourth	1.17 (1.04-1.32)	.008	NA	NA
Type of supplemental insurance [reference, public]				
Medicare HMO	1.80 (1.55-2.08)	<.001	1.80 (1.57-2.05)	<.001
Private	2.38 (2.09-2.71)	<.001	1.82 (1.62-2.05)	<.001
None	2.86 (2.48-3.29)	<.001	2.91 (2.57-3.29)	<.001
Disease [reference, none]				
Cancer	1.86 (1.55-2.23)	<.001	1.47 (1.20-1.79)	<.001
Noncancer condition <sup>c</sup>	1.82 (1.69-1.97)	<.001	1.69 (1.57-1.83)	<.001

Abbreviations: HMO, health maintenance organization; NA, not applicable.

<sup>a</sup> Values represent estimates from multivariable logistic regression. The regression model is adjusted for age, sex, race/ethnicity, educational level, marital status, geographic region, self-assessed health, comorbidities, smoking status, baseline wealth quartile (only for out-of-pocket expenditures), and survey wave. Results for geographic region are not displayed owing to table length. High out-of-pocket expenditures and financial burden refer to participants with out-of-pocket expenditures and financial burden in the highest decile of the distribution of out-of-pocket expenditures and financial burden, respectively.

<sup>b</sup> Wealth was not included as a covariate in logistic regression examining financial burden.

<sup>c</sup> Heart disease, dementia, stroke, type 1 or 2 diabetes, or lung disease.

**Table 3. Adjusted Level of OOP Expenditures and Financial Burden in Patients With Newly Diagnosed Cancer**

Characteristic	Mean	Median	90th Percentile
OOP expenditures, \$ <sup>a</sup>			
Medicaid [reference]	2116	1123	7860
Veterans Health Administration	2367 <sup>b</sup>	1265 <sup>b</sup>	8008
Medicare HMO	5976 <sup>b</sup>	3052 <sup>b</sup>	10 761
Employer-sponsored insurance	5492 <sup>b</sup>	2663 <sup>c</sup>	11 437
Medigap	5670 <sup>b</sup>	3122 <sup>b</sup>	11 755
None	8115 <sup>b</sup>	3743 <sup>b</sup>	17 866 <sup>c</sup>
Financial burden, % <sup>d</sup>			
Medicaid [reference]	8.5	2.2	24.3
Veterans Health Administration	5.4 <sup>e</sup>	3.8	27.8
Medicare HMO	13.2 <sup>e</sup>	8.0 <sup>b</sup>	35.7
Employer-sponsored insurance	12.6 <sup>e</sup>	6.3 <sup>c</sup>	37.2
Medigap	14.1 <sup>c</sup>	8.0 <sup>b</sup>	38.8
None	23.7 <sup>b</sup>	11.3 <sup>b</sup>	63.1 <sup>c</sup>

Abbreviations: HMO, health maintenance organization; OOP, out-of-pocket.

<sup>a</sup> Values represent estimates from multivariable generalized linear regression or quantile regression models. Regression models were adjusted for age, sex, race/ethnicity, educational level, marital status, geographic region, self-assessed health, comorbidities, smoking status, baseline wealth quartile (only for OOP expenditures), and survey wave.

<sup>b</sup>  $P < .001$ .

<sup>c</sup>  $P < .01$ .

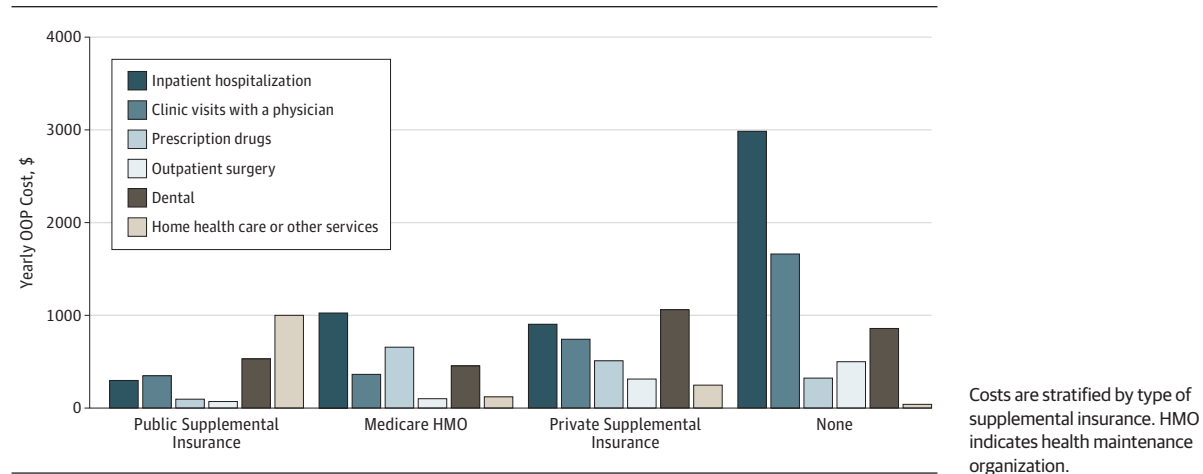
<sup>d</sup> Financial burden = OOP expenditures/total household income.

<sup>e</sup>  $P < .05$ .

following the diagnosis compared with patients with Medicaid coverage (Medicaid, \$2116; Veterans Health Administration, \$2367; Medicare HMO, \$5976; employer-sponsored insurance, \$5492; Medigap, \$5670; and none, \$8115;  $P < .001$  for

all) (Table 3). Notably, patients without supplemental insurance experienced the highest mean annual OOP expenditures despite having less income and wealth than patients with all other insurance arrangements except for patients with

**Figure. Mean Out-of-Pocket (OOP) Costs for Individual Cost Categories Among Patients Newly Diagnosed With Cancer**



Medicaid coverage. Similarly, patients without supplemental insurance experienced the greatest financial burden, spending a mean of 23.7% of their total annual household income on OOP expenditures (Table 3). At the 90th percentile, patients lacking supplemental insurance spent 63.1% of their total annual household income on OOP expenditures.

Among patients with cancer, OOP costs from inpatient hospitalization exceeded OOP costs from other service categories. More important, inpatient hospitalization was the primary driver of high OOP expenditures in patients with cancer, representing 42% of total OOP expenditures for patients with OOP costs in the highest decile. The Figure illustrates the contribution of individual OOP cost categories to total OOP costs for patients with cancer, stratified by type of supplemental insurance. Out-of-pocket costs from inpatient hospitalization varied significantly depending on type of supplemental insurance, ranging from 12% of total OOP costs for patients with Medicaid or Veterans Health Administration coverage to 46% for patients lacking supplemental insurance. A total of 380 patients with cancer (27.0%) reported multiple inpatient hospitalizations during the survey interval in which they were diagnosed, but there was no difference in hospitalizations based on insurance classification (65 of 227 patients [28.6%] with public supplemental insurance; 64 of 251 patients [25.5%] with Medicare HMO; 200 of 744 patients [26.9%] with private supplemental insurance; and 51 of 187 patients [27.3%] with no supplemental insurance). Out-of-pocket costs from other service categories also varied based on supplementary insurance type, but the differences were far less pronounced (eTable 3 in the Supplement).

Since medical expenditures associated with cancer care generally follow a U-shaped pattern, with the highest expenditures occurring after initial diagnosis and at the end of life, we also analyzed OOP expenditures at the end of life.<sup>36</sup> Specifically, we measured OOP expenditures incurred in the period between the last survey administration and date of death for 1489 participants who either died of cancer between 2002 and 2012 or were actively receiving cancer treatment at the end of life (eTable 4 in the Supplement). As the median time from

the last survey administration to date of death was 1.3 years (interquartile range, 0.8-1.9 years), OOP expenditures were normalized to an annual scale. Findings in decedents with cancer were similar to those newly diagnosed; decedents with cancer who were lacking supplemental insurance experienced the highest level of OOP expenditures at the end of life (eTable 5 in the Supplement), and inpatient hospitalization was the primary contributor to high OOP costs at the end of life (eFigure in the Supplement).

## Discussion

A new diagnosis of cancer imposes significant financial strain on community-dwelling, fee-for-service Medicare beneficiaries who lack supplemental insurance. Nearly 10% of elderly patients with Medicare alone spent more than 60% of their annual household income on OOP expenditures following a diagnosis of cancer. More important, costs associated with inpatient hospitalization accounted for approximately 40% of total OOP expenditures in patients with cancer who had high OOP costs, including more than 40% of total OOP expenditures in patients with cancer who had Medicare alone; beneficiaries with supplemental coverage were generally protected from high hospital-associated OOP costs. Similar patterns of OOP costs were seen in Medicare beneficiaries who died of cancer.

Inpatient hospitalization represents the largest component of Medicare spending on cancer, both in the initial phase of treatment as well as at the end of life, and is a primary source of regional variation.<sup>37,38</sup> Although our study was limited by the HRS cost category definitions in its attribution of costs, our results illustrate that inpatient hospitalization may also contribute significantly to high OOP spending in elderly patients with cancer, both at the initial diagnosis and at the end of life, supporting efforts to reduce hospital-associated costs among patients with cancer.<sup>39-49</sup>

As an example from our institution, recent construction of an oncology-specific urgent care clinic dramatically re-

duced rates of hospitalization in patients undergoing cancer therapy. Among those treated with radiotherapy, for instance, the mean number of patients who were hospitalized during their course of radiotherapy or within 60 days thereafter decreased from 35 per month to 18 per month following the opening of the oncology-specific urgent care clinic. More important, 35 of 352 hospitalizations (9.9%) during this time resulted in patient liabilities in excess of \$2000; among Medicare beneficiaries without supplemental insurance, 4 of 39 hospitalization-associated patient liabilities (10.3%) exceeded \$10 000.

Beyond highlighting the need for innovative initiatives for delivery of care, the high level of hospital-associated OOP costs may also demonstrate potential adverse consequences of Medicare's current design of benefits. For 2016, Medicare's deductible for Part B services is \$166, while its Part A hospital-stay deductible is \$1288 per 90-day benefit period.<sup>50</sup> Assigning beneficiaries such a high responsibility of cost sharing for inpatient care may not be an effective use of cost sharing, as hospitalizations are usually not at the discretion of beneficiaries. In the HRS cohort, for example, the frequency of hospitalization did not vary with insurance status. Instead, a unified deductible for all medical services may be a more prudent arrangement and is a feature of several proposals for Medicare reform.<sup>51-54</sup> More important, these proposals also stipulate an annual maximum on OOP expenditures, another key reform to protect seniors against catastrophic costs.<sup>51-54</sup> As an example, 73 of 187 patients (39.0%) with cancer in the HRS cohort with Medicare alone experienced OOP costs in excess of the \$5500 OOP limit specified in a Congressional Budget Office plan.<sup>51</sup>

### Limitations

Although our study has many strengths, important limitations must be acknowledged. Foremost, OOP expenditure data were based on patient self-report, which is subject to recall bias. Survey data are also subject to misclassification and incomplete reporting, although the latter is minimized by the HRS bracketing approach. More important, granular detail on specific services that contributed to OOP costs was limited by the HRS-defined cost categories, and variability in the manner in which costs were assigned by participants may have existed. For example, OOP costs from outpatient radiotherapy services were presumably assigned by participants to the category of clinic visits with a physician, but this categorization cannot be verified.

In addition, variability in site of chemotherapy administration likely resulted in its assignment to multiple categories, with inpatient administration of intravenous chemotherapy, for example, likely included in the category of inpatient hospitalization. This possibility may explain the high OOP costs for inpatient admission found in this study. Furthermore, limited information on tumor type and stage prevented further stratification by these key variables. As such, future research to define specific tumor-associated and/or treatment-associated services that contribute to OOP costs should be conducted, perhaps through collaborations with payers that track OOP costs. Moreover, we did not have information on length of stay, including observation status, which can expose beneficiaries to high OOP costs and was becoming increasingly prevalent during the study period.<sup>55,56</sup> In addition, while our findings in patients who lacked supplementary insurance more broadly reflect the financial effect of cost sharing, Medigap and employer-sponsored insurance plans vary in their generosity of benefits, which we were not able to incorporate into our analysis. Furthermore, our data cannot be extrapolated to the nonelderly and nursing home residents, who were excluded from the study, although our findings may still have implications for younger Americans considering less generous health exchange plans that require significant cost sharing. In addition, our comparisons of the OOP costs between cancer and other chronic conditions assume similar U-shaped cost curves, the applicability of which is unclear for patients with newly diagnosed chronic conditions. Furthermore, the distribution of types of supplemental insurance may not reflect current conditions, particularly with respect to employer-sponsored insurance, as retiree benefits are less generous now than at the beginning of the study period. Finally, our measure for OOP expenditures did not include premiums, an important component of total OOP spending.

### Conclusions

Medicare beneficiaries without supplemental insurance incur significant financial burden following a diagnosis of cancer. More important, inpatient hospitalization may represent a key contributor to high OOP costs. Proposals for Medicare reform that restructure the design of benefits for hospital services and incorporate an OOP maximum may help alleviate the risk of financial burden for future beneficiaries, as can interventions that reduce hospitalizations in this population.

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### Invited Commentary

## Mitigating Financial Toxicity Among US Patients With Cancer

Jonas A. de Souza, MD, MBA; Rena M. Conti, PhD

**Treatment for cancer** is undergoing a renaissance. However, the “financial toxicity” of cancer treatment for US patients and their families is a growing concern.<sup>1</sup> Financial distress among patients with cancer includes high out-of-pocket (OOP) spending relative to income and assets, loss of work, and significant household debt. Financial distress is associated with growing reports of delayed initiation of treatment, limited patient adherence, and abandonment of recommended treatment, which erodes the effectiveness of cancer treatment and even hastens death.

The study by Narang and Nicholas<sup>2</sup> in this issue of *JAMA Oncology* fills some important gaps in our current understanding of financial distress among patients with cancer. The authors use national data from 1409 patients with cancer eligible for Medicare insurance coverage and surveyed by the Health and Retirement Study between 2002 and 2012. Narang and Nicholas<sup>2</sup> estimate inflation-adjusted annual OOP spending following a cancer diagnosis and patients’ financial burden, defined as the ratio of OOP spending to household income, overall and stratified by the existence and type of supplemental insurance coverage. The authors report that



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the mean annual OOP spending and financial burden amounted to \$3737 and 11.4%, respectively. Higher OOP spending was associated with less generous supplemental insurance coverage; \$2116 among those insured by Medicaid, \$2367 among those insured by the Veterans Health Administration, \$5976 among those insured by a Medicare health maintenance organization, \$5670 among those with Medigap insurance coverage, and \$8115 among those insured by traditional fee-for-service Medicare but without supplemental insurance coverage. Medicare beneficiaries newly diagnosed with cancer with no supplemental insurance coverage incurred mean OOP spending amounting to 23.7% of their household income. Ten percent of these individuals incurred OOP spending amounting to 63.1% of their household income.

These results suggest that physicians and policy makers should be particularly concerned about potential financial distress experienced by Medicare beneficiaries without supplemental insurance coverage or underinsured by existing policies. This is an important finding given that the number of

underinsured US patients—those covered by high-deductible health plans and plans requiring patients to pay coinsurance (a percentage of a medical charge), rather than copayments (a flat fee), when care is provided—is growing. Monthly income for seniors derived from Social Security benefit payments alone has also stagnated since the Great Recession. This finding also suggests that the development of tools aimed at helping patients navigate the financial consequences of their cancer diagnosis and treatment may be particularly fruitful when targeted to underinsured individuals. Relief is likely to come in the form of value-based insurance design or other refinements to existing insurance policies.<sup>3,4</sup>

This study also raises 3 priority areas for future research aimed at helping formulate interventions to prevent or mitigate financial distress among patients with cancer. First, more research is needed about which care components induce financial distress and for which patients. Much recent emphasis has been placed on patient financial distress associated with new anticancer drugs,<sup>5</sup> while other studies have suggested that nonpharmaceutical care components may also be important contributors to patient financial toxicity. For example, de Souza et al<sup>6</sup> suggest that patients with cancer experiencing 3 or more admissions to the hospital in a given year self-report high financial distress, when measured by the validated COMprehensive Score for Financial Toxicity instrument. Narang and Nicholas<sup>2</sup> also report that patient financial toxicity appears to be concentrated among inpatient costs incurred with cancer treatment. Although this finding is provocative, significant data limitations prevented them from distinguishing between OOP spending associated with hospital inpatient stays from OOP spending associated with chemotherapy administered in the inpatient and outpatient settings. Data limitations also prohibited Narang and Nicholas<sup>2</sup> from attributing financial burden to care undergone by patients with specific types or stages of cancer or receiving specific lines of therapy. This limitation is important for future research to examine since care components may differ substantially across types of cancer and existing insurance benefits can act to shield patients from financial distress associated with specific care components but not others.

Second, systematic understanding of what types of charitable aid is already being provided to patients with cancer is