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Patient–Provider Discussions About Out-of-Pocket Costs of Cancer Care in the U.S

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Abstract

Introduction: Despite the importance of cost-related discussions in cancer care, little is known about the prevalence or drivers of these discussions in clinical practice. This study estimates the prevalence and examines the correlates of cancer survivors' discussions about out-of-pocket costs of cancer care with providers.

Methods: The 2016 and 2017 Medical Expenditure Panel Survey Experiences with Cancer Surveys were used to identify 1,550 survivors who responded to the question on discussion about out-of-pocket costs of cancer care. Multivariable multinomial logistic regression examined the correlates of discussions about out-of-pocket costs. Analyses were performed in 2019.

Results: Approximately one quarter of cancer survivors reported having discussed the out-of-pocket costs of cancer care. In multivariable analyses, respondents in the following categories were less likely to report no cost discussion than any cost discussion: black non-Hispanic/other race (RRR=0.67, 95% CI=0.45, 0.98; white non-Hispanic race as reference), no health insurance at diagnosis (RRR=0.51, 95% CI=0.27, 0.95; private health insurance as reference), and any experience of financial hardship (RRR=0.48, 95% CI=0.35, 0.66; no financial hardship as reference).

Conclusions: Patient-reported discussions about out-of-pocket costs for cancer care are infrequent in the U.S. The findings highlight the needs to improve the understanding of the barriers and facilitators for effective discussions about out-of-pocket costs of cancer care.

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INTRODUCTION

In the past few decades, technological innovations in oncology have substantially improved the detection, diagnosis, and treatment of cancer, albeit accompanied by rapidly escalating costs of cancer care.[1] The rising costs of cancer care have triggered efforts by insurers to shift a greater burden of these costs to the patients through deductibles, copayments, and coinsurance.[2,3]

Cost sharing can adversely affect the access to high-quality cancer care and patients' quality of life.[4-6] Patients with cancer are more than 2.5 times more likely to declare bankruptcy than those without a cancer diagnosis.[7] Among cancer survivors, bankruptcy is associated with increased mortality.[8] To address the concerns about the affordability of cancer care, the American Society of Clinical Oncology convened a Task Force on the cost of cancer care in 2007. In its 2009 guidance statement, the Task Force recognized the centrality of discussing costs as a component of high-quality care and recommended that oncologists be armed with information that will help them appraise and communicate the value of specific cancer treatments.[9] As many patients may be forced to compensate for high out-of-pocket costs by delaying or abandoning treatment, reducing adherence to prescription drugs, and skipping physician appointments,[6,10] effective cost communication can inform treatment planning and facilitate referral to financial navigation services, thereby improving access to cancer care. Furthermore, surveys suggest that majority of cancer patients and survivors desire to discuss out-of-pocket costs of treatment, and these discussions may enhance patient satisfaction with care.[11-13]

The importance of cost-related discussions in cancer care notwithstanding, evidence suggests that these discussions occur infrequently in clinical practice.[14] Much less is known about the potential factors driving the discussions about out-of-pocket costs of cancer care, such as health insurance coverage and patient financial vulnerability. This study presents national estimates of the prevalence of patient–provider discussions about the out-of-pocket costs of cancer care in the U.S. and examines the patient-level correlates of these discussions.

METHODS

Study Sample

The Medical Expenditure Panel Survey (MEPS) is a nationally representative household survey of U.S. civilian non-institutionalized population on healthcare utilization and costs. This study used data from the 2016 and 2017 MEPS supplemental Experiences with Cancer surveys.[15] The response rates for the 2016 MEPS were 46.0% overall and 81.2% among those eligible to complete the Experiences with Cancer survey; the corresponding rates for 2017 were 44.2% and 82.4%, respectively.[16,17]

The Experiences with Cancer survey was used to identify the cancer survivors who responded to the question on discussion about out-of-pocket costs with any healthcare provider. Consistent with previous literature, those respondents whose only cancer diagnosis was a nonmelanoma skin cancer (n=231) were excluded.[18,19] The analytic sample consisted of 1,550 cancer survivors.

Measures

The outcome measure was derived from the response to the question: *At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you your costs of cancer care paid out of your own pocket?* There were 4 possible responses: *discussed it with me in detail, briefly discussed it with me, did not discuss it at all, or I don't remember.*

Respondent characteristics included age, sex, race/ethnicity, marital status, education, insurance coverage at the time of cancer diagnosis, time since last cancer treatment (<1 year/currently receiving treatment, 1–3 years, 4–5 years, and >5 years/never treated, derived from the responses to the survey question about duration since last treatment and evidence of cancer-directed treatments in the core MEPS files), and out-of-pocket costs in the year before the survey.

We also included an indicator for any experience of material, psychological, or behavioral financial hardship related to cancer or its treatment. Material financial hardship was identified from the responses to 4 questions in the survey wherein the respondents were asked whether they ever (1) had to borrow money or go into debt, (2) had to file for bankruptcy, (3) had to make financial sacrifices, or (4) were unable to cover their share for medical care visits because of cancer or its treatment.

Measures of behavioral financial hardship included ever having delayed, forgone, or made other changes to the following cancer care because of cost: (1) prescription medicine, (2) visit to specialist, (3) treatment other than prescription medicine, (4) follow-up care, (5) mental health services, or (6) other services. Psychological financial hardship was identified from the respondents' reports of ever worrying about (1) having to pay large medical bills, (2) their family's financial stability, or (3) keeping their job and income because of cancer or its treatment. This scheme of classifying financial hardship is similar to previous research in this area.[20] A composite measure of intensity of financial hardship was created as the total number of domains with an affirmative response to an individual question (0, 1, or ≥2).

Statistical Analysis

Response distributions were computed in the entire sample, in specific age groups and categories of financial hardship, and by the time since last cancer-directed treatment. In supplemental analyses, response distributions were stratified by quartiles and intensity of out-of-pocket spending (<20% or >20% of family income) in the past year.

A multivariable multinomial logistic approach was used to examine the associations between respondent characteristics and 3 levels of cost discussions: *no discussion, don't remember*, and *any discussion* (derived by combining the *brief discussion* and *detailed discussion* response categories). A supplemental approach used a generalized ordered logistic model (details are provided in Appendix, available online). Analyses were performed in the entire sample and among those treated within 5 years of the survey. All analyses were conducted in

2019 using Stata/IC, version 14, with variance estimation strata and weights to account for the survey design and nonresponse.

RESULTS

Descriptive characteristics of patients are presented in Table 1. Approximately 45% of cancer survivors were treated within 5 years of the survey or were currently receiving treatment. In the full sample, 6% of the respondents reported being uninsured at the time of diagnosis and, approximately 59% had experienced any financial hardship related to cancer or its treatment. The corresponding proportions among those treated within 5 years of the survey were approximately 5% and 63%, respectively. About 51% of the respondents in the entire sample and 55% among those treated within 5 years experienced material financial hardship—the most common among the 3 domains. Approximately 40% in the full sample and 45% among those treated within 5 years reported 2 or more domains of financial hardship. Less than 5% of the respondents had out-of-pocket spending >20% of family income and about a quarter had out-of-pocket spending >$1,500.

Figure 1 shows the distribution of responses to the questions about out-of-pocket cost discussions. Approximately 23% of cancer survivors in the entire sample reported having discussed the out-of-pocket costs of cancer care with any provider at any time since diagnosis. Higher percentage of respondents who were treated more recently reported having received any cost discussion, with the proportions ranging from approximately 19% among those treated >5 years ago to about 28% among the most recently treated. The proportion of respondents who reported not remembering any cost discussions ranged from 20.4% among those treated >5 years ago to 8.4% among those most recently treated. Approximately 30% of respondents aged 18–44 years and 17% of those aged ≥75 years reported having any cost discussions. Among those who reported any financial hardship, approximately 29% reported having discussed out-of-pocket costs; the corresponding proportion among those not reporting financial hardship was approximately 15%.

Appendix Tables 1 and 2 (available online) show the quartile distribution of out-of-pocket costs of the previous year in the entire sample and among those treated within 1 year of the survey. The proportion of respondents who reported any cost discussion was higher among those with out-of-pocket spending >20% of family income as compared with others (35% versus 22.4% in the entire sample). However, only about 4% of respondents had out-of-pocket spending >20% of family income. Clear trends were not visible in the response distributions based on out-of-pocket spending quartiles (Appendix Figures 1 and 2, available online).

Results from the multinomial logistic regressions are shown in Table 2. Respondents aged ≥75 years were more likely to report no cost discussion than any cost discussion (RRR=1.85, 95% CI=1.02, 3.34; reference aged 18–44 years). Respondents in the following categories were less likely to report no cost discussion than any cost discussion: black non-Hispanic/other race (RRR=0.67, 95% CI=0.45, 0.98; white non-Hispanic race as reference), no health insurance at diagnosis (RRR=0.51, 95% CI=0.27, 0.95; private health insurance as reference), and any experience of financial hardship (RRR=0.48, 95% CI=0.35, 0.66; no financial hardship as reference).

Similar associations were observed among the subgroups of respondents who were treated within 5 years of the survey. However, the RRRs in this analysis were not statistically significant for most respondent categories, likely owing to the smaller sample and diminished statistical power.

Inferences drawn from the ordinal logistic regressions were consistent with those from the multinomial regressions (Appendix Table 3, available online).

DISCUSSION

This study indicates that despite concerns regarding the affordability of cancer care,[3,9,21] patient–provider discussions about out-of-pocket costs for cancer care are infrequent in the U.S. In this nationally representative sample of cancer survivors, less than one quarter of patients reported ever having had any conversation about out-of-pocket costs with any provider at any time since diagnosis. Less than one third of survivors in all categories of age, time since last treatment, and experiences of financial hardship reported having conversations about out-of-pocket costs. Similar rates of cost communications among cancer survivors have been reported previously. A meta-analysis of studies conducted predominantly in small, single-institution samples of cancer survivors estimated that 27% of interviewed patients had cost communications with their physicians.[14]

The 2 indicators of potential financial vulnerability—absence of health insurance at diagnosis and any experience of financial hardship since diagnosis—were positively associated with the discussions about out-of-pocket costs. These findings are consistent with the previous literature reporting that higher subjective financial distress is associated with a greater likelihood among survivors to desire a cost discussion.[22] Furthermore, many cost discussions are initiated by providers,[23] and insurance status is a likely objective indicator of potential patient financial vulnerability. Indeed, health insurance coverage is a common topic discussed in oncologist-initiated cost conversations.[24] High out-of-pocket costs are a major impediment to access to high-quality cancer care among the uninsured, and more frequent discussions about costs with this population are necessary. However, it is equally important to note that even cancer survivors with comprehensive health insurance coverage may incur substantial out-of-pocket costs, face distress, have trouble paying medical bills, and delay or forgo medical care because of cost.[3] High cost sharing through deductibles, copayments, and coinsurance accounts for a considerable portion of total out-of-pocket costs. As the proportion of the U.S. population enrolled in high-deductible plans continues to rise,[25] there is a growing need to incorporate the discussions about out-of-pocket costs in the process of informed decision making, irrespective of providers' or patients' anticipations of cost burden.

Although the discussions about out-of-pocket costs were more common among survivors who had experienced any financial hardship due to cancer or its treatment, only about 30% of survivors in this group reported having received any cost conversations with any provider since diagnosis. Previous surveys of oncologists and patients with cancer have shown that despite the patients' desire to discuss out-of-pocket costs with their oncologists[11,12] and the recognition of the importance of managing out-of-pocket costs by majority of the oncologists,[26,27] discussions about these costs in oncologist–patient encounters are infrequent.[12,28,29] Common barriers to cost discussions experienced by patients with cancer include discomfort in initiating the discussion, the belief that a discussion would not reduce the costs of treatments, and concerns that discussing costs may adversely affect the quality of care.[22] Some physicians too may be unprepared to discuss treatment costs,[27] miss patients' cues about their financial concerns,[30] or may face systemic barriers to cost discussions such as lack of price transparency or time.[30] Not all cost discussions may happen in a clinician's office and barriers may exist in the workflow for referring patients to other members of the care team such as financial counselors, financial navigators, or social workers who may be better informed and trained to conduct these discussions. Overall, the preponderance of survivors in this study who reported not having any cost discussion despite experiencing financial hardship underscores these barriers and motivates future research to better understand them and focused interventions to counter them.

This study found that age ≥75 years was associated with the lower likelihood of discussion about out-of-pocket costs. The finding could be, in part, an artifact of recall bias, as older age may be correlated with poorer memory. It is also possible that adults aged ≥75 years received less-intensive or less-expensive therapies, which affected the perceived need for cost communications.[31] Another possible explanation for this association could be that for the providers, a survivor's age may act as a proxy for their coverage by Medicare, even in the absence of actual documentation of their insurance status in their notes.

Limitations

It is important to note some limitations of this study. First, the data were self-reported and were subject to recall bias. With majority of the respondents in the survey being long-term survivors of cancer, it was neither feasible nor informative to restrict all analyses only to the most recently treated respondents. Besides, given the lasting effects of cancer or its treatment, many patients with cancer continue to endure the burden of out-of-pocket costs throughout the survivorship phase of care[18,32,33]; thus, discussions about out-of-pocket costs may be required at different points along the cancer continuum. Alternatively, the survey provided an opportunity to account for a potential recall bias by including *don't remember* as a distinct response category. A multi-variable multinomial approach was used to examine the associations between the 3 response categories and measures of financial vulnerability, including health insurance coverage, experience of financial hardship, and educational level of the respondents, whereas controlling for potential correlates of recall such as age and time since treatment. Supplemental analyses were conducted using an ordered logistic approach to allow a conservative assessment of the correlates of absence of cost discussions. The inferences drawn from the 2 regression models were similar. To further minimize the effect of recall bias, a subgroup analysis was conducted among those respondents who received cancer-directed treatment within 5 years of the survey. The results from this analysis were in the same direction as those for the full sample; however, some associations were no longer statistically significant, likely in part because of the smaller sample size. The authors acknowledge that despite the use of multiple analytic approaches, the possibility of recall bias affecting the inferences cannot be ruled out. Future studies should address this limitation by surveying larger cohorts of recently diagnosed or treated survivors. Presently, the MEPS Experiences with Cancer survey is the only source of nationally representative information on cancer survivors' discussions about out-of-pocket costs with providers. Questions about out-of-pocket health care costs and discussions about these costs with providers need to be incorporated into more household surveys. Overall, the findings of this study are more pertinent to cost discussions in the entire survivorship phase and highlight the need for more research about discussions that happen around the time of diagnosis and initial treatment.

Second, some potential correlates of cost discussions, including the type of cancer treatment, and details of health insurance benefit design, out-of-pocket costs, and comorbidities at the time of diagnosis, were either not available or inconsistently available in the survey. Although some treatment types could be identified in the most recently treated group using the core MEPS data, their numbers were insufficient for statistical analyses. For instance, 57 among 389 most recently treated respondents were identified as the recipients of chemotherapy/hormonal therapy/radiotherapy in the past year. Although the authors did use the core MEPS data to stratify response distributions among recently treated respondents based on past-year out-of-pocket spending, these results were less informative because of small sample sizes. In future, larger and more detailed data will be required for a more in-depth assessment of the drivers of cost discussions among cancer survivors.

Finally, the survey did not include information to examine additional important questions about cost discussions such as whether respondents desired to discuss out-of-pocket costs and whether their financial concerns were appropriately addressed during the discussion.

CONCLUSIONS

This study is the first nationally representative assessment of the prevalence of patient–provider discussions about out-of-pocket costs of cancer care. The findings highlight the need for research efforts aimed at securing a better understanding of the barriers and facilitators to patient–provider discussions about out-of-pocket costs of cancer care. In addition, little is known about whether and how discussions about out-of-pocket costs modify patients' financial burden or their quality of care. Among the sparse research in this domain is a study of recorded conversations among 677 patients with breast cancer and 56 oncologists, which found that common cost-reducing strategies discussed included switching to a lower cost therapy and changing the timing, source, or location of care.[34] Another smaller study of 300 patients with cancer found that among those who received a cost discussion, 57% reported lower out-of-pocket costs as a result of the discussion.[30] The methods of cost reduction included physicians' referral to a financial assistance program, advocacy or facilitation of the insurance approval/coverage process, switching to lower cost prescriptions, and changing or decreasing the number of tests.[30] Future research should focus on establishing clear linkages between the discussions about out-of-pocket costs, implementation of cost reduction strategies, and their effect on the quality of care. Furthermore, effective cost discussions are much less likely to happen if the providers do not have access to real-time data on patient out-of-pocket cost implications of specific treatment decisions. Thus, more price data need to be made available and policies to improve price transparency need to be instituted. In addition, it would be helpful to develop guidelines and training modules for clinicians and others in the care team on screening patients for cost communications and the optimal timing and content of discussions about out-of-pocket costs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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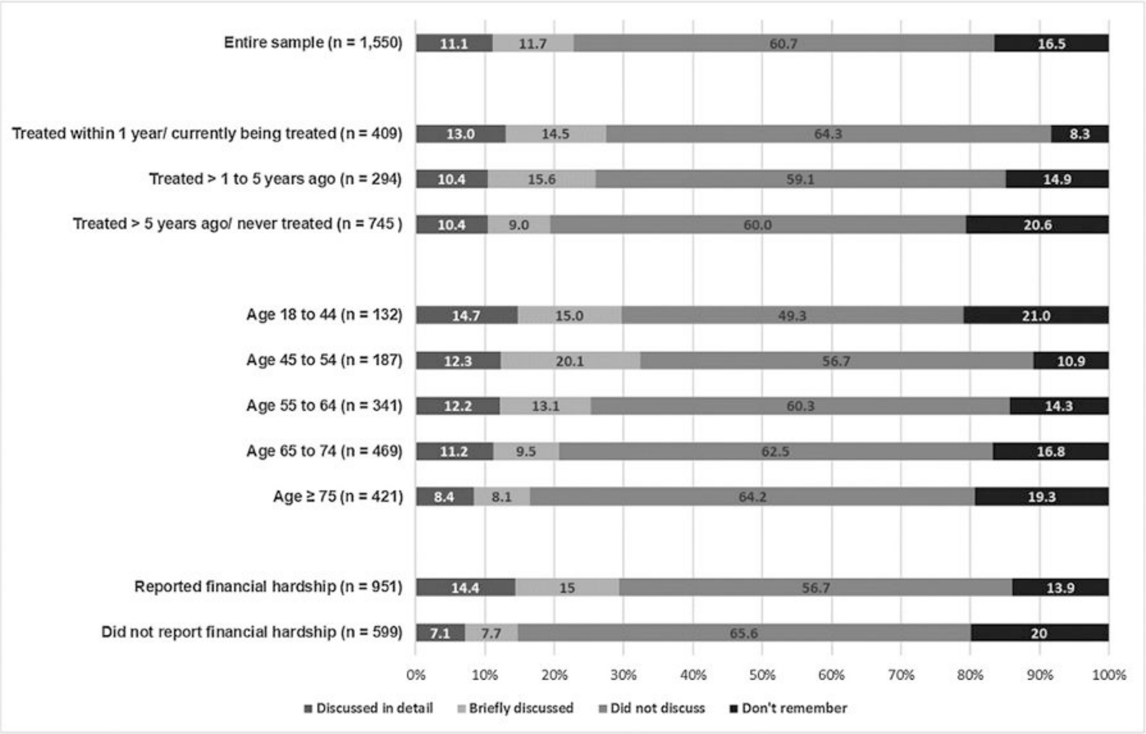

Figure 1.

Distribution of responses to the questions about out-of-pocket cost discussions with any provider. Data Source: 2016–2017 Medical Expenditure Panel Survey Experiences with Cancer Survey.[15,16,17]

Table 1.

Sample Characteristics of Respondents to the 2016–2017 Medical Expenditure Panel Survey Experiences With Cancer Survey

Characteristics	**All respondents, *n* (weighted %)**	**Treatment ≤5 years of the survey, *n* (weighted %)**
Total	1,550 (100)	703 (100)
Age, years		
18–44	132 (7.8)	68 (8.1)
45–54	187 (12.4)	96 (15.5)
55–64	341 (22.6)	170 (23.3)
65–74	469 (30.4)	203 (30.0)
≥75	421 (26.8)	166 (23.2)
Sex		
Female	912 (42.8)	397 (56.2)
Male	638 (57.2)	306 (43.9)
Race/ethnicity		
White non-Hispanic	1,122 (81.8)	589 (88.4)
Black non-Hispanic/others	428 (18.2)	114 (11.6)
Marital status		
Currently married	834 (57.6)	392 (60.2)
Other	716 (42.4)	311 (39.8)
Education		
Less than high school/missing[a]	283 (13.8)	131 (13.4)
High school	649 (41.5)	284 (40.6)
College/advanced degree	618 (44.7)	288 (46.0)
Insurance status at the time of diagnosis		
Any private	916 (63.7)	399 (64.0)
Public only	390 (21.9)	199 (23.3)
Uninsured	119 (6.0)	51 (5.2)
Not ascertained	125 (8.4)	54 (7.6)
Time since last cancer treatment[b]		
<1 year/currently receiving treatment	409 (25.4)	409 (56.9)

Characteristics	**All respondents, *n* (weighted %)**	**Treatment ≤5 years of the survey, *n* (weighted %)**
1–3 years	145 (9.4)	145 (21.0)
4–5 years	149 (9.6)	149 (22.1)
>5 years/never treated	745 (48.1)	
Not ascertained	102 (6.6)	
Ever experienced material/psychological/behavioral financial hardship related to cancer or its treatment		
Yes	951 (58.7)	459 (63.0)
Ever experienced material financial hardship related to cancer or its treatment		
Yes	822 (50.8)	399 (55.2)
Ever experienced psychological financial hardship related to cancer or its treatment		
Yes	511 (31.6)	283 (38.5)
Ever experienced behavioral financial hardship related to cancer or its treatment		
Yes	492 (28.5)	231 (29.1)
Intensity of financial hardship related to cancer or its treatment[c]		
0	599 (41.3)	244 (37.1)
1	308 (19.2)	137 (18.5)
≥2	643 (39.5)	322 (44.5)
Out-of-pocket spending >20% of family income		
Yes	76 (3.5)	39 (4.3)
Out-of-pocket spending >$1,500		
Yes	356 (25.2)	181 (28.7)

[a] <0.5% missing.

[b] Derived from the responses to the survey question about duration since last cancer treatment and evidence of chemotherapy, hormone therapy, or radiotherapy in the year preceding the survey in the core MEPS files.

[c] Total number of domains of financial hardship (material, psychological, and behavioral) with at least 1 affirmative response to an individual question.

Table 2.

Factors Associated With Cost Discussions, 2016–2017 Medical Expenditure Panel Survey Experiences With Cancer Survey

	Entire sample (*n*=1,550)		Treated <5 years of the survey (*n*=703)	
	No discussion versus any discussion, RRR (95% CI)	**Do not remember versus any discussion, RRR (95% CI)**	**No discussion versus any discussion, RRR (95% CI)**	**Do not remember verses any discussion, RRR (95% CI)**
Age, years				
18–44	ref	ref	ref	ref
45–54	1.02 (0.53, 1.97)	0.49 (0.22,1.10)	1.06 (0.44, 2.56)	0.60 (0.17, 2.11)
55–64	1.30 (0.74, 2.30)	0.78 (0.38, 1.62)	0.96 (0.43, 2.14)	0.61 (0.18, 2.10)
65–74	1.45 (0.82, 2.55)	0.94 (0.46,1.93)	1.66 (0.76, 3.62)	1.47 (0.49, 4.41)
≥75	**1.85 (1.02, 3.34)** *	1.17 (0.57, 2.40)	1.66 (0.73, 3.80)	1.20 (0.36, 3.95)
Sex				
Female	ref	ref	ref	ref
Male	0.80 (0.60, 1.08)	**0.60 (0.40, 0.92)** *	0.67 (0.43, 1.05)	0.76 (0.41,1.41)
Race/ethnicity				
White non-Hispanic	ref	ref	ref	ref
Black non-Hispanic/others	**0.67 (0.45, 0.98)** *	0.76 (0.42, 1.38)	0.63 (0.37, 1.07)	1.44 (0.64, 3.29)
Marital status				
Currently married	ref	ref	ref	ref
Others	0.99 (0.70, 1.41)	1.19 (0.75,1.88)	1.08 (0.67,1.74)	1.51 (0.77, 2.95)
Education				
Less than high school/missing	ref	ref	ref	ref
High school	1.35 (0.88, 2.09)	0.82 (0.48, 1.40)	1.68 (0.92, 3.06)	0.76 (0.33,1.72)
College/advanced degree	1.43 (0.90, 2.26)	**0.54 (0.30, 0.99)** *	1.55 (0.86, 2.78)	**0.34 (0.14, 0.87)** *
Insurance status at the time of diagnosis				
Any private	ref	ref	ref	ref
Public only	1.18 (0.82, 1.68)	1.08 (0.67, 1.73)	1.17 (0.72, 1.89)	1.31 (0.62, 2.76)
Uninsured	**0.51 (0.27, 0.95)** *	0.90 (0.47,1.71)	0.68 (0.29, 1.62)	0.58 (0.17,1.98)
Not ascertained	1.18 (0.67, 2.07)	1.46 (0.75, 2.84)	1.29 (0.58, 2.86)	0.68 (0.16, 2.80)
Time since last cancer treatment				

	Entire sample (n=1,550)		Treated <5 years of the survey (n=703)	
	No discussion versus any discussion, RRR (95% CI)	**Do not remember versus any discussion, RRR (95% CI)**	**No discussion versus any discussion, RRR (95% CI)**	**Do not remember verses any discussion, RRR (95% CI)**
<1 year/currently receiving treatment	ref	ref	ref	ref
1–3 years	0.85 (0.50, 1.45)	2.11 (0.98, 4.54)	0.82 (0.48,1.38)	2.16 (1.00, 4.66)
4–5 years	1.05 (0.60, 1.82)	1.78 (0.81, 3.90)	1.02 (0.59, 1.79)	1.82 (0.82, 4.04)
>5 years/never treated	1.23 (0.92, 1.66)	**3.24 (1.87, 5.60)** **	—	—
Not ascertained	0.99 (0.52, 1.91)	**2.85 (1.30, 6.23)** **	—	—
Ever experienced material/psychological/behavioral financial hardship related to cancer or its treatment				
No	ref	ref	ref	ref
Yes	**0.48 (0.35, 0.66)** **	**0.40 (0.26, 0.61)** **	**0.52 (0.32, 0.83)** *	**0.41 (0.20, 0.83)** *

Note: Boldface indicates statistical significance

* $p<0.05$

** $p<0.01$.