

# The Utility of Cost Discussions Between Patients With Cancer and Oncologists

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Cancer treatment in the United States or Europe costs well over \$100 billion a year,<sup>1,2</sup> and with increases in cost sharing,<sup>3</sup> insured patients with cancer and cancer survivors experience substantial financial burdens.<sup>4</sup> Although the Affordable Care Act (ACA) has improved access to care, many patients who enroll in bronze and some silver plans still face considerable out-of-pocket costs in the form of high deductibles and coinsurance.<sup>5</sup> Hence, questions remain regarding how well insured patients will cope with costs in the healthcare reform setting.

Treatment-related financial burdens can impair patients' quality of life and diminish the quality of cancer care.<sup>4,6,7</sup> Not unlike the physical side effects associated with chemotherapy, cancer treatment might also be financially toxic.<sup>8</sup> For example, those with a cancer diagnosis are more than twice as likely to declare personal bankruptcy than those without a cancer diagnosis.<sup>9</sup> The financial impact of cancer care might also extend beyond patient well-being into patient care quality; patients on oral anticancer therapy with higher co-payments are more likely to be nonadherent to those drugs.<sup>10,11</sup>

Due to the mounting financial burden associated with cancer care, physicians, patients, and policy makers face a growing mandate to integrate costs into clinical decision making.<sup>12</sup> The Institute of Medicine (IOM) issued a report on quality cancer care with a recommendation to provide patients with understandable information on costs.<sup>13</sup> However, little is known about patients' preferences for incorporating cost discussions into cancer treatment decision making and the ramifications of those discussions.

We conducted a cross-sectional study to determine if patients wanted to discuss the cost of treatment with doctors, if patients wanted to incorporate cost into treatment decision making, and if patients found cost discussions useful in lowering out-of-pocket expenses.

## ABSTRACT

**Objectives:** Patients with cancer can experience substantial financial burden. Little is known about patients' preferences for incorporating cost discussions into treatment decision making or about the ramifications of those discussions. The objective of this study was to determine patient preferences for and benefits of discussing costs with doctors.

**Study Design:** Cross-sectional, survey study.

**Methods:** We enrolled insured adults with solid tumors on anti-cancer therapy who were treated at a referral cancer center or an affiliated rural cancer clinic. Patients were surveyed at enrollment and again 3 months later about cost discussions with doctors, decision making, and financial burden. Medical records were abstracted for disease and treatment data. Logistic regression investigated characteristics associated with greater desire to discuss costs.

**Results:** Of 300 patients (86% response rate), 52% expressed some desire to discuss treatment-related out-of-pocket costs with doctors and 51% wanted their doctor to take costs into account to some degree when making treatment decisions. However, only 19% had talked to their doctor about costs. Of those, 57% reported lower out-of-pocket costs as a result of cost discussions. In multivariable logistic regression, higher subjective financial distress was associated with greater likelihood to desire cost discussions (odds ratio [OR], 1.22; 95% CI, 1.10-1.36). Nonwhite race was associated with lower likelihood to desire cost discussions (OR, 0.53; 95% CI, 0.30-0.95).

**Conclusions:** Patients with cancer varied in their desire to discuss costs with doctors, but most who discussed costs believed the conversations helped reduce their expenses. Patient-physician cost communication might reduce out-of-pocket costs even in oncology where treatment options are limited.

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### Take-Away Points

Patients with cancer varied in their desire to discuss costs with doctors; most who discussed costs believed the conversations helped reduce their expenses. Communication on cost has the potential to reduce out-of-pocket costs, even in oncology, where treatment options are limited.

- These results immediately impact cancer care as patients with cancer face higher out-of-pocket costs than those with other chronic illnesses.
- This work adds to the literature by describing the impact of cost discussions on patient costs and decision making.
- This work is key to healthcare reform since under the Affordable Care Act, a majority of Americans are signing up for high cost-sharing plans. Physicians and policy makers face a growing mandate to integrate costs into clinical decision making.

## METHODS

### Patients

We enrolled a convenience sample of adult patients at a comprehensive cancer center and at 3 affiliated, rural, oncology clinics between November 2012 and June 2013. Potential participants were identified via review of clinic schedules. Eligible patients had public or private insurance coverage, had a confirmed solid tumor cancer diagnosis, and were receiving anticancer hormonal therapy or chemotherapy for at least 1 month at the time of enrollment.

We excluded the uninsured, those receiving radiation therapy, and non-English-speaking patients. Uninsured patients were excluded since we were focused primarily on the experiences of patients who are insured but were still at risk of financial distress. The underinsured are especially important to study since the hazard of underinsurance might remain despite the ACA.<sup>5</sup> Patients receiving radiation therapy were excluded due to the relatively short nature of a typical course of radiation therapy.

Eligible, consecutive (ie, no special selection in advance) patients were approached while waiting in clinic or while waiting to receive chemotherapy. However, due to study staff availability, not every potentially eligible patient was screened or approached for study participation. After obtaining informed consent, trained interviewers surveyed patients in person at the time of enrollment; 3 months after completion of the baseline survey, interviewers again surveyed patients by phone or in person. Participants were given \$10 for completion of the baseline interview and another \$10 for completion of the 3-month follow-up interview.

### Data Collection

Data were collected via abstraction of the medical record and patient interview. We developed study-specific baseline and 3-month follow-up surveys. The follow-up survey—identical to the baseline survey minus demographic sur-

vey items—was administered to determine whether preferences for cost discussions changed over time. Demographic survey items were adapted from those used in the national Cancer Care Outcomes Research and Surveillance (CanCORS) study<sup>14</sup> and a survey-based survivorship study.<sup>15</sup>

Items regarding cost-related decision making were developed for this study. We asked participants, “How much do you want to talk to your doctor about your cancer-related out-of-pocket costs?” This item was scored on scale of 1 (“not at all”) to 10 (“a great deal”). We asked participants, “Do you want your cancer doctor to take your costs into account when he/she decides how to treat your cancer?” This item was scored on scale of 1 (“never”) to 10 (“always take costs into account”). We surveyed participants about perceived barriers to cost discussions and factors that motivated them to discuss costs. Patients who discussed costs with their oncologists were asked: 1) whether the cost discussion decreased their out-of-pocket costs, and 2) what changes in treatment plan decreased costs.

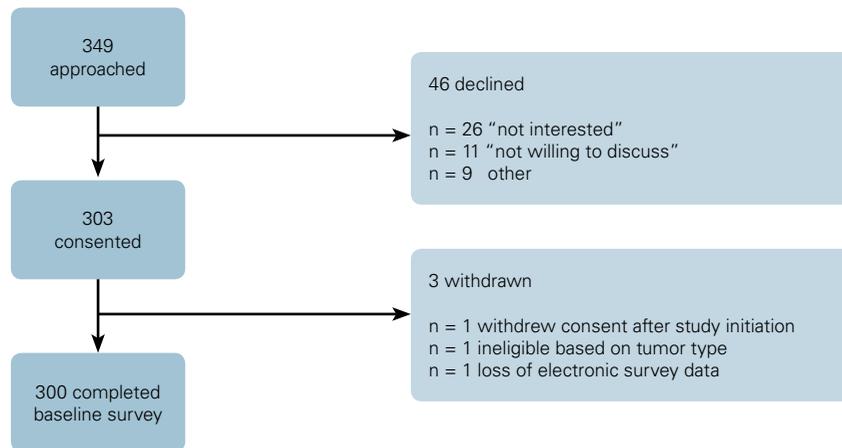
Survey items regarding general clinical decision-making preferences were adapted from CanCORS.<sup>16</sup> Financial distress was measured using a validated 8-question scale used in the financial planning community but not previously used in clinical research.<sup>17</sup> For consistency with the other measures, the financial distress measure is reported as an inverted score of 1 (“least financial distress”) to 10 (“greatest financial distress”), rather than the original scoring where 1 was associated with greatest distress. Objective financial burden was measured using items from our prior study regarding out-of-pocket expenses related to cancer care.<sup>7</sup> Overall quality of life was assessed using a validated, single-item, linear analogue self-assessment with a scale of 0 (“as bad as can be”) to 10 (“as good as can be”).<sup>18</sup> All survey items were piloted in 20 patients to review questions for readability and comprehension.

The medical record was abstracted for cancer diagnosis, stage, type of treatment, and duration of treatment at the time of enrollment. The Duke University Medical Center Institutional Review Board approved this study.

### Statistical Analysis

To assess generalizability of these findings, we compared age, disease characteristics, and treatment characteristics of patients who chose to participate to those who declined participation. We summarized descriptive variables including demographics, clinical, and financial characteristics. Changes in participant response between baseline and

■ **Figure 1.** Cohort Diagram



follow-up survey were assessed using McNemar's test for matched pairs. The primary logistic regression model investigated characteristics associated with a greater patient desire to discuss costs with doctors, using responses to the question, "How much do you want to talk to your doctor about your cancer-related out-of-pocket costs?"

The primary outcome was dichotomized as a yes/no variable with a response  $>1$  scored as some desire to discuss costs based on distribution of participant responses, since nearly 50% of the cohort chose the lowest possible value of 1, corresponding to "not at all." We included in the regression model any variables from bivariate analyses that differed with a  $P < .05$ . Further, additional covariates of interest were included in the regression model. Statistical analyses were performed using SAS version 9.3 (SAS Institute, Cary, North Carolina).

## RESULTS

### Patients

Of 349 consecutive patients approached, 300 were eligible and agreed to participate (86% response rate) (Figure 1). Participants ( $n = 300$ ) and nonparticipants ( $n = 46$ ) were similar in terms of median days on treatment, treatment location, primary site of cancer, stage of disease, and receipt of oral chemotherapy (all  $P > .05$ ). Participants were younger than nonparticipants (60 vs 67 years;  $P = .006$ ). Of the 300 who completed the baseline survey, 246 (82%) completed the 3-month follow-up survey. Patient characteristics are described in Table 1. At the time of study enrollment, all patients were insured, 97% had prescription drug coverage, and all patients were receiving chemotherapy or hormonal therapy.

### Do Patients Want to Discuss Costs With Their Oncologists?

Fifty-two percent ( $n = 155$ ) of patients expressed a desire to discuss treatment-related out-of-pocket costs with their doctor (Figure 2A). Forty-eight percent chose the lowest possible value of 1, corresponding to "not at all." Another 15% chose the middle value of 5, and 9% chose the highest value of 10, corresponding to "a great deal." The rest of the sample had a nearly uniform distribution between remaining values. However, only 19% ( $n = 56$ ) had actually talked to their doctor about their out-of-pocket costs. That 56 was comprised of 49 (32%) of the 155 participants who said they had any desire to discuss costs and 7 (5%) of the 144 participants who said they had no desire at all to discuss costs. Additionally, 76% ( $n = 227$ ) of patients believed that their doctor did not know how much they paid out-of-pocket for their cancer care.

Common reasons given for both discussing costs and avoiding cost discussions are listed in Table 2. A majority of patients did not discuss costs because they "had no difficulties affording care." The most common factor that prompted cost discussion was high out-of-pocket cost for prescription medications.

### Do Patients Want to Include Costs in Treatment Decision Making?

Overall, 51% ( $n = 153$ ) wanted their doctor to take costs into account to some degree when making cancer treatment decisions. However, although 21% ( $n = 62$ ) always wanted costs taken into account (Figure 2B), 30% of patients had responses distributed fairly evenly between "always" and "never take costs into account."

### Did Cost Discussions Lower Out-of-Pocket Costs?

Of the 19% (n = 56) who reported talking to their doctors about costs, 57% (n = 32) reported lower out-of-pocket costs as a result of that cost discussion. Per patient report, common means to cost reduction included the physician referring the patient to a financial assistance program (53%), the physician advocating for the patient or facilitating the insurance approval/coverage process (25%), switching to less expensive prescription medications (19%), changing or decreasing the number of tests (13%), or decreasing the number of doctor visits (6%).

### Timing of Cost Discussions

A higher proportion of patients at 3 months versus baseline were willing to discuss costs with their doctors (59% vs 50%, respectively; *P* = .02), but overall time on treatment was not associated with desire to discuss costs. A higher proportion of patients at 3 months versus baseline had spent all or a portion of their savings (52% vs 40%, respectively; *P* < .01). A higher proportion of patients at 3 months versus baseline believed their doctor was aware of their out-of-pocket costs (12% vs 4%; *P* < .01). However, in comparison with baseline, a similar proportion of patients reported high or overwhelming financial distress, and a similar proportion had discussed costs upon follow-up.

### Financial Burden

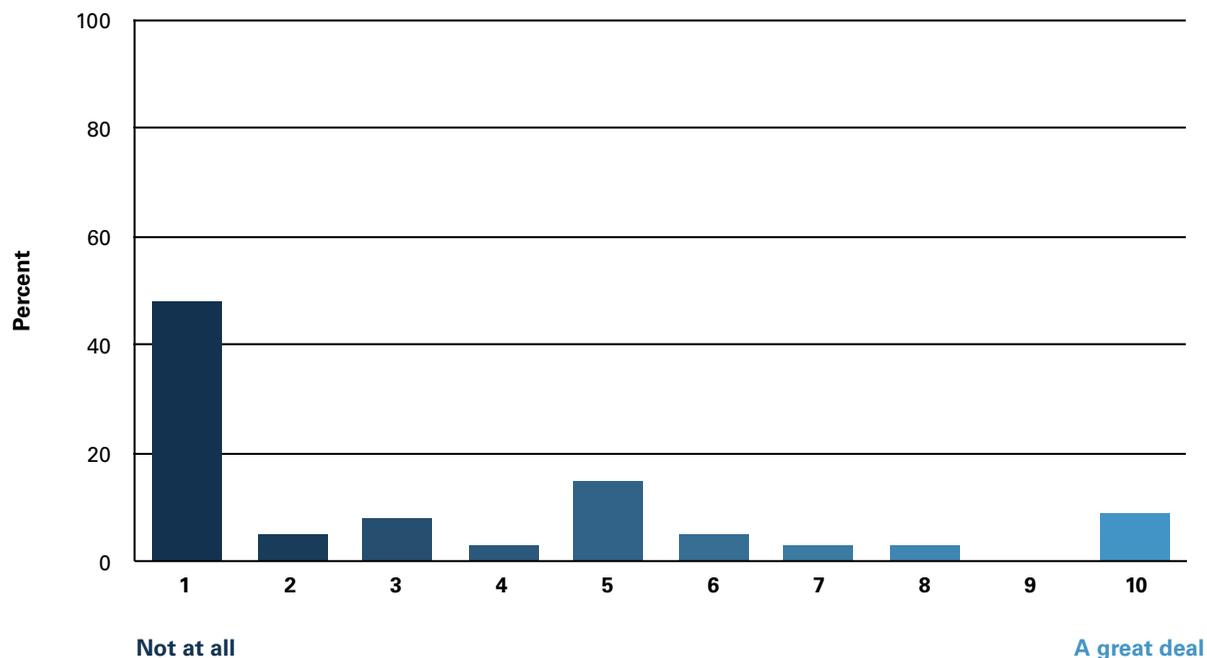
Median patient-reported out-of-pocket healthcare costs were \$592 per month (range = \$3-\$47,250 per month). The median financial distress score at baseline was 3.62 (range = 1-10) with 1 representing the least financial distress and 10 representing the greatest. Sixteen percent of patients reported high or overwhelming financial distress (with a score of 8-10); these patients also had higher median out-of-pocket costs compared with patients reporting low/average financial distress (\$728/month vs \$565/month; *P* = .03). Forty-one percent of patients reduced spending

■ **Table 1.** Demographic and Clinical Characteristics

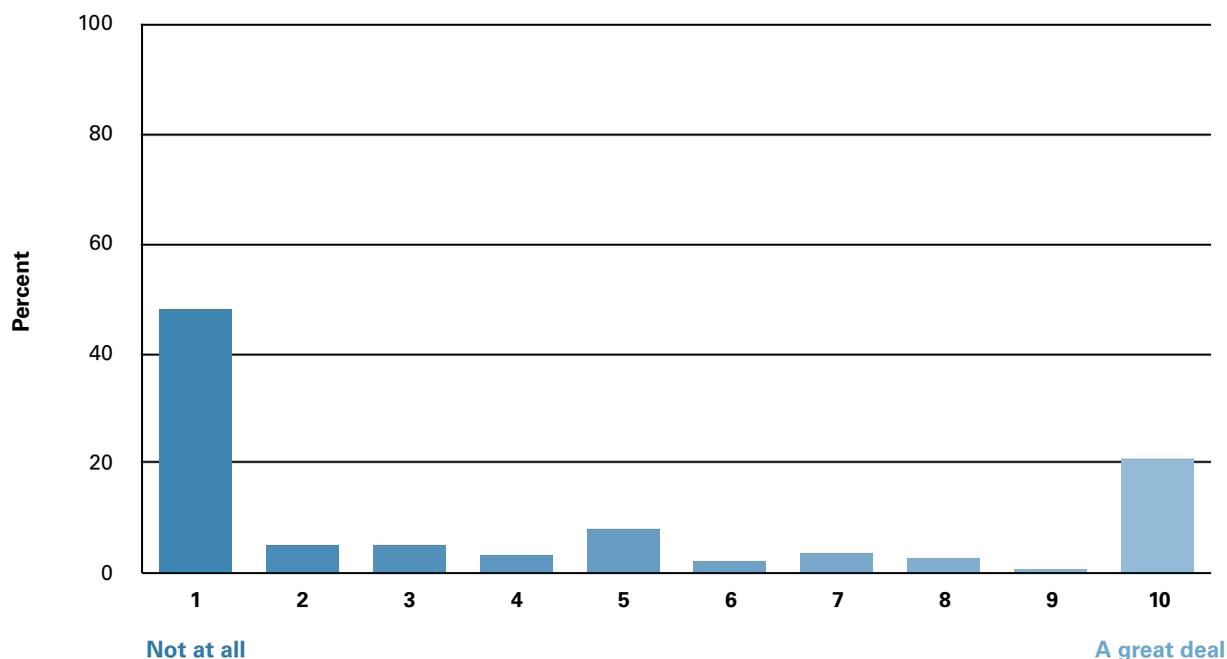
<b>n = 300</b>	
<b>Age, median (min-max), years</b>	60 (27-91)
<b>Gender (male)</b>	157 (52%)
<b>Race</b>	
White	226 (75%)
African-American	58 (19%)
American Indian/Alaskan Native	7 (2%)
Other	3 (1%)
Missing, refused, unknown	3 (1%)
<b>Education</b>	
High school, GED, or less	83 (28%)
Associates degree or some college	86 (29%)
Bachelor's degree	71 (24%)
Master's or other advanced degree	60 (20%)
<b>Annual household income,<sup>a</sup> median (min-max)</b>	\$60,000 (\$0-\$450,000)
<b>Insurance status</b>	
Private	168 (56%)
Medicare	107 (36%)
Medicaid	22 (7%)
Other	3 (1%)
<b>Married/living with partner</b>	205 (69%)
<b>Prescription drug coverage</b>	290 (97%)
<b>Employment status</b>	
Employed full time	80 (27%)
Employed part time	18 (6%)
Retired	110 (37%)
Unemployed and not seeking	79 (26%)
Unemployed and seeking	1 (<1%)
Other	12 (4%)
<b>Cancer diagnosis</b>	
Colorectal	81 (27%)
Breast	53 (18%)
Lung	52 (17%)
Pancreaticobiliary	39 (13%)
Prostate	22 (7%)
Other	53 (18%)
<b>Stage at enrollment</b>	
Local	30 (10%)
Regionally advanced/unresectable	35 (12%)
Distant/metastatic	235 (78%)
<b>Days on treatment at enrollment, median (min-max)</b>	140 (30-950)
<sup>a</sup> n = 215.	

on leisure activities like vacations, eating out, or movies in order to pay for cancer care, and 27% reduced spending on basic needs like food or clothing. Forty percent used

**Figure 2A.** How Much Do You Want to Talk to Your Doctor About Cancer-Related Out-of-Pocket Costs? (n = 299)



**Figure 2B.** How Much Do You Want Your Doctor to Take Costs Into Account When He/She Decides How to Treat Your Cancer? (n = 300)



■ **Table 2.** Common Reasons for Discussing Costs and Avoiding Cost Discussions

Why haven't you talked about costs with your doctor?	n = 243
I have no difficulties affording care	130 (53%)
I want the best possible care regardless of costs	83 (34%)
My doctor shouldn't have to worry about my finances/not my doctor's job	55 (23%)
My doctor doesn't know how to help or would not be able to help with my costs	46 (19%)
I have talked to someone else (like a social worker or counselor) about my costs of care	27 (11%)
I am embarrassed about discussing costs with my doctor	12 (5%)
Other	8 (3%)
Refused	1 (<1%)
What prompted you to talk about your costs with your doctor?	n = 56
High out-of-pocket cost for prescription drugs	13 (23%)
My doctor brought up the topic of costs	11 (20%)
Other high treatment-related out-of-pocket costs	7 (13%)
Insurance-related issue or question	4 (7%)
I have difficulty affording basics like food or clothing	2 (4%)
I have to cut back on leisure activities like eating out or movies	2 (4%)
I have to use my savings to help pay for my care	10 (18%)
I have to borrow or use credit to help pay for my care	8 (14%)
I entered the Medicare donut hole	8 (14%)
Other	11 (20%)
Multiple responses were allowed. N = 299; 1 participant declined to respond.	

all or a portion of their savings to pay for cancer care, and 19% borrowed money or used credit.

In multivariable logistic regression (Table 3), higher subjective financial distress was associated with a greater likelihood to desire a cost discussion and nonwhite race was associated with a lower likelihood to desire a cost discussion. Annual household income was not included in the primary logistic regression due to missing data (7% of patients did not report their income). Hence, we conducted secondary analyses to determine whether income was associated with a desire to discuss costs. First, we determined that missing data in the income variable was random and not associated with a desire to discuss costs ( $P = .07$ ). Second, we conducted a sensitivity analysis with income included in the multivariable logistic regression model, and income was not associated with a desire to discuss costs (eAppendix, available at [www.ajmc.com](http://www.ajmc.com)).

## DISCUSSION

Patient out-of-pocket healthcare costs compromise patient care and harm patient well-being.<sup>6,9,19</sup> Nevertheless,

little is known about whether patients want to discuss costs with their oncologist and whether those discussions are helpful in reducing out-of-pocket costs. Understanding the interaction of financial burden, cost discussion, and treatment decision making is particularly important in oncology, where expensive interventions may produce marginal results.<sup>20-22</sup>

In this study, patients with cancer receiving treatment varied in their desire to discuss costs with doctors, with nearly half stating no desire to discuss costs, most of whom stated they did not have difficulties affording care. Yet, most who talked to their doctors about costs believed the conversations helped reduce their costs. Our findings suggest, first: a broad range of patient preferences and circumstances should be considered when taking cost discussions into account, and second, patient-physician cost communication might reduce out-of-pocket costs even in oncology where treatment options are often limited.

We found wide variation in the degree to which patients wanted to have that discussion, with nearly half reporting no desire to discuss costs with their doctors. A similar array of responses was elicited when patients were

■ **Table 3.** Multivariable<sup>a</sup> Logistic Regression Assessing Patient Characteristics Associated With Greater Likelihood of Having a Cost Discussion

Variable	Odds Ratio	95% CI	P
Age (continuous)	1.06	0.93-1.20	.41
Female gender	0.91	0.57-1.46	.69
Nonwhite race vs white	0.53	0.30-0.95	.03
Financial distress (continuous)	1.22	1.10-1.36	<.01
Private insurance vs nonprivate	1.05	0.58-1.90	.87
Part- or full-time employment vs unemployed	1.00	0.57-1.75	1.00

<sup>a</sup>Variables assessed in univariate analysis included the above and income, roundtrip distance traveled to clinic, quality-of-life score, receipt of oral versus intravenous chemotherapy, cancer stage, marital status, monthly out-of-pocket costs, education, reduction on leisure spending due to treatment costs, reduction on basics spending due to treatment costs, using savings for cancer care, using credit for cancer care, skipping medications, taking less medications, and not filling prescriptions.

asked if they wanted costs included in treatment decision making; while just under half the cohort never wanted costs to be considered in treatment decision making, 21% always wanted costs taken into account. This spectrum of responses may present a challenge to physicians intent on delivering preference-sensitive care, especially since financial distress screening tools have not been widely tested as a part of standard practice.

With such wide variation in cost discussion preferences, are cost discussions worth pursuing in clinic, where time is limited? We found that more than half of patients who discussed finances with their doctor reported lower out-of-pocket costs as a result of that discussion. Most of the time, costs were reduced without actually changing the care that was delivered. These findings are noteworthy, especially since patients were reluctant to discuss costs for fear they might receive lesser quality care. Whereas many patients expressed concern that their doctors would be unhelpful in reducing their costs, our data suggests that some oncologists have adopted practices to lower patient costs without impacting care quality.

Our study is not the first to describe patient-reported barriers to cost communication,<sup>23</sup> and other studies have described numerous barriers from physicians' perspectives. First, physicians frequently report feeling ill-prepared or uncomfortable with discussing costs with patients.<sup>24-26</sup> Second, lack of price transparency might make cost predictions difficult if not impossible.<sup>27</sup> Third, particularly in treating cancer, finding less expensive treatment alternatives might be challenging. Despite these well-described patient- and physician-reported barriers to effective cost discussions, our study adds to this literature by finding that patients report lower out-of-pocket costs due to fairly straightforward interventions that did not

require special training or in-depth knowledge of costs. Research should further test the effectiveness of practice-based, cost-related alterations in care.

Our study cohort is not representative of all patients with cancer in the United States, where in 2012, roughly 15% of patients were uninsured.<sup>28</sup> However, our findings are remarkable for the degree of financial burden experienced by this insured population of patients with cancer, the vast majority of whom also had prescription drug coverage. With a median age nearing retirement, more than half of the cohort spent all or a portion of their savings to pay for cancer care, and a quarter used credit. Thirty percent reduced spending on groceries or clothing to defray cancer care-related costs. These data are consistent with other studies that confirm the financial burden shouldered by cancer patients and survivors.<sup>4,9,29</sup> Furthermore, the insured population is important to study based on increasing cost sharing and the potential for experiencing high coinsurance under the silver- or bronze-level plans under the ACA.<sup>35</sup>

White patients reported a greater willingness to discuss costs than nonwhite patients. A comprehensive body of literature has described differences in communication and decision-making preferences by race or ethnicity.<sup>30</sup> For example, black patients might be more likely to be less active in the decision-making process, receive less information from their doctors, and subsequently, have lower trust in their physicians.<sup>31,32</sup> Our data suggest that means to promote cost discussion preferences in minority populations should be studied further.

Along with race, high financial distress was the only other measure associated with a greater willingness to discuss costs with a doctor. Further, although financial distress was unchanged over time, upon follow-up, patients were more likely to have spent all or part of their savings

on treatment-related expenses. These findings suggest that discussions of cost need not be limited to an initial visit when the time in clinic might best be devoted to focusing on the implications of disease and treatment. If cost of care is incorporated in clinical decision making—as recommended by the IOM<sup>33</sup>—novel measures of financial burden must be integrated into the growing library of patient-reported data collection tools.

### Limitations

Our study is subject to several limitations. We surveyed a consecutive but nonrandom sample of patients with cancer—most of whom were treated at a major referral center. However, the study had a high response rate and nonresponders only differed to responders in age, suggesting that at least within this center, this was a representative population. Furthermore, the median monthly out-of-pocket cost estimates provided by study participants approximated those from larger, population-based studies.<sup>29,34</sup> Since not all potentially eligible patients were approached due to study staff availability, selection bias might have been introduced. Although the desire to discuss costs was not measured via a validated measure, no validated instruments were available to measure this outcome. The follow-up interval of 3 months was short, but the majority of patients on our study had advanced cancer where survival is measured in months, not years. Upon follow-up, patients' desire to discuss cost might have been influenced by study participation since time on treatment was not associated with a change in desire to discuss costs. Only a small number of patients reported having cost discussions, and we relied on patient self-report. However, since financial distress is a subjective measure, it might be useful to study perceived cost reductions.

### CONCLUSIONS

As healthcare costs continue to rise, we must acknowledge the effect of those costs on patients. Even though our findings suggest heterogeneity among cancer patients in regards to cost discussion preferences, most of those who broached the topic found help in reducing their expenses despite well-described barriers to effective cost discussions. These results identify key areas of research. First, more work needs to be done to identify patients who might desire or benefit from a cost discussion. Second, studies of recorded patient-physician encounters might clarify which factors promote or discourage cost discussions at the moment of clinical decision making. Third, further research should validate practice-based interventions to

reduce out-of-pocket costs similar to those reported in this study. Although lack of price transparency and limited time in clinic might present barriers to cost discussions, the impact of financial burden on patients suggests these barriers must be overcome to deliver high-value, patient-centered cancer care.

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**eAppendix.** Sensitivity Regression Analysis: Results of Model Selection With Anchored Variables Including Income Range Variable

<b>Odds Ratio Estimates and Confidence Intervals</b>				
	<b>Label</b>	<b>Estimate</b>	<b>95% CI</b>	<b><i>P</i></b>
Age unit = 5 years		1.079	0.945-1.233	.2616
Gender: female vs male		0.945	0.572-1.563	.8262
Race: nonwhite vs white		0.540	0.287-1.015	.0555
Inverted, continuous FD		1.235	1.102-1.386	.0003
Income range	At least \$20,000 but less than \$40,000 vs less than \$20,000	0.243	0.044-1.340	.1044
Income range 2	At least \$40,000 but less than \$60,000 vs less than \$20,000	0.558	0.110-2.833	.4815
Income range 3	At least \$60,000 or more vs less than \$20,000	0.912	0.320-2.598	.8626
Private insurance vs nonprivate		1.073	0.577-1.997	.8243
Partially or fully employed vs unemployed		0.894	0.502-1.592	.7035