

Understanding Patients' Attitudes Toward Communication About the Cost of Cancer Care

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Abstract

Purpose: Recent publications have promoted physician-patient communication on cost as a means of decreasing overall spending and minimizing patients' financial burden in oncology. No study has assessed patients' perspectives on cost communication in oncology. We sought to describe oncology patients' attitudes toward cost communication, explore potential predictors for patients' communication preferences, and assess how patients with cancer consider cost when making management decisions.

Methods: A 31-item questionnaire was developed to measure oncology patients' communication preferences regarding the cost of cancer care, focusing on out-of-pocket costs. Items were adapted from other instruments when possible. After piloting, patients were recruited from an academic ambulatory oncology practice. Basic descriptive statistics were applied.

Results: Of the 771 patients approached, 256 responded (response rate, 33%). Most (68%) preferred to know about out-of-pocket costs before treatment. A majority (59%) wanted their physician to discuss these costs with them. Although 76% reported feeling comfortable discussing cost with their physician, 74% were amenable to discussing cost with someone other than their physician. Most patients did not consider out-of-pocket costs (57%) or the health care costs of the country (61%) in their decision making, nor did they believe their physician should (55%). Patients receiving active chemotherapy were less likely to want to discuss out-of-pocket costs with their physician ($P = .035$).

Conclusion: Patients' comfort with and desire to discuss cancer costs exceed that of oncologists, suggesting a need to educate oncologists on this important topic. A patient's desire to understand treatment-associated cost does not equate with a desire for cost to influence medical decision making.

Introduction

Technologic advances have led to substantial progress in cancer detection, prevention, and treatment, resulting in reduced cancer-specific mortality. These advancements, however, have also contributed significantly to the rapidly rising health care costs that affect both individual patients and society at large. Cancer care accounted for an estimated \$104.1 billion in medical expenditures in the United States in 2006¹ and increased to \$124.6 billion in 2010.² In 2007, 40% of Medicare drug spending was attributed to drugs prescribed by oncologists,³ and by 2020, the National Institutes of Health estimate that cancer costs will total more than \$200 billion.⁴ As the US population ages, these costs are predicted to increase substantially.

Recent publications, including the 2009 American Society of Clinical Oncology cost of cancer care guidance statement,⁵ have promoted physician-patient communication on cost as a means of decreasing overall spending and minimizing patients' financial burden. Financial discussions between patients and their oncologists have the potential to affect not only the cost of care but also cancer outcomes and patient satisfaction. Patient preferences regarding cost communication are currently unknown. Thus evidence to guide oncologists' approach to such discussions is needed.

Studies show that most oncologists feel uncomfortable and ill equipped to lead cost discussions.^{6,7} A substantial minority of oncologists argue further that cost discussions may complicate and even compromise the physician-patient relationship.^{6,8} Re-

search involving primary care patients suggests that a majority of patients want to discuss out-of-pocket costs with their inter-nists.⁹ However, this finding may not extend to patients with cancer. In fact, studies suggest that some patients with cancer place greater value on treatments than do the general public and their health care providers.¹⁰⁻¹² They may also prefer to discuss sensitive topics with someone other than their oncologist.¹³

To date, no data exist on preferences of patients with cancer regarding cost communication. In this study, we sought to describe patients' attitudes toward discussing cancer costs with their oncologist, assess how patients consider cost when making management decisions in oncology, and explore possible associations between patient characteristics and their communication preferences.

Methods

Survey Development

This cross-sectional descriptive pilot study was designed to assess communication preferences among a cohort of outpatient oncology patients diagnosed with solid tumor malignancies using a unique self-administered questionnaire. When possible, items were adapted from relevant, previously validated instruments.^{6,9,14} The survey instrument consisted of 31 items covering several domains, including: patient demographics, socioeconomic status, cancer diagnosis, health insurance coverage, personal experience with cancer treatment, communication

preference, extent of cost burden related to cancer care, and influence of cost on medical decision making. A majority of questions regarding cost communication focused specifically on out-of-pocket costs. Respondents were also invited to provide optional written comments. The survey was piloted by six oncology nurses, 10 oncology physicians, and 17 oncology patients and adapted based on their feedback. Approval to administer the survey was obtained from the hospital internal review board.

Survey Administration

All patients scheduled to see a medical oncologist specializing in solid tumor malignancies at Beth Israel Deaconess Medical Center in Boston, Massachusetts, during February 2010 were asked to participate. When checking in for their appointment, patients were provided with a cover letter inviting their participation and explaining the goals of the study. Those who agreed to participate were then asked to complete the questionnaire during the visit and return it to a locked collection box in the clinic waiting room. Participants were asked to complete the questionnaire only once.

Participants were also asked to provide optional written informed consent for a limited medical record review. If permission was granted, the investigators reviewed the medical record for accurate cancer staging information and treatment history.

Analytic Strategies

Primary and secondary end points. The primary objective was to obtain descriptive data regarding patients' attitudes toward communication about cost of cancer care. The secondary objective was to explore predictors of patients' communication preferences with regard to out-of-pocket costs.

Sample size and power. We aimed to enroll a convenience sample of 250 participants to capture a broad range of tumor diagnoses as well as time since diagnosis, thereby providing a representative sample of patients with cancer in our academic oncology practice. Statistical analysis further supported an accrual goal of 250 patients. On the basis of a review of monthly clinical activity, the estimated eligible patient population was approximately 2,000 patients over a 2-month period. Subsequent sample size calculations revealed that between 235 and 322 patients would be required to demonstrate 5% to 6% CIs with 95% certainty. Assuming a recruitment rate of 10% to 15%, we anticipated accrual of 250 participants within an 8-week period.

Statistical Considerations

The primary aim of the study was to present descriptive data regarding oncology patients' preferences for discussing cancer costs, with a majority of questions focusing on out-of-pocket costs. Basic descriptive statistics were applied, including frequencies, medians, and proportions. We evaluated associations between responses using simple frequencies and evaluated the bivariate relationships between survey items using cross tabulations. Given that the primary outcome of

interest was descriptive cross-sectional data, missing data were censored.

The secondary aim of the study was to explore associations between patients' communication preferences regarding out-of-pocket costs and other measured factors including demographics, experience with cancer, and cost burden. A single Likert scale item served as the dependent variable: "I would like my doctor to talk with me about my out-of-pocket costs when he/she recommends a cancer test or treatment." Independent variables were represented by the remaining items in the survey. Bivariate analyses were performed using the Fisher's exact test statistic to identify factors associated with patients' preferences for cost communication. The *P* value was set at less than .05.

Results

Study Population

Of 771 patients approached for study participation in the outpatient oncology unit at Beth Israel Deaconess Medical Center, 256 returned questionnaires, for a response rate of 33%. Recruitment, which was planned for 8 weeks, was stopped after 3 weeks because the targeted sample size had been obtained. Respondent demographics are listed in Table 1. Consent for the limited medical record review was provided by 171 participants (64%).

Communication Preferences

Responses regarding communication preferences are shown in Figure 1A. A majority of respondents (59%) wanted to discuss out-of-pocket costs with their physician, and an even greater majority (76%) was comfortable discussing cancer costs with their physician. A substantial minority of respondents (30%) preferred to discuss costs with someone other than their physician. Of those who did not wish to discuss cost with their physician, 50% expressed a preference to do so with someone other than their physician ($P = .039$).

Cost Burden

One fourth of respondents agreed that paying for their cancer care was difficult, and 14% reported financial hardship as a result (Fig 1B). Twenty-nine percent reported having to make sacrifices as a result of paying for their cancer care. Examples included: forgoing vacations, paying bills late, missing mortgage or college tuition payments, not taking medications as prescribed, and omitting alternative therapies. Reporting financial hardship or burden did not influence out-of-pocket communication preferences.

Influence of Cost on Decision Making

Participants' preferences regarding how cost should influence decision making are shown in Figure 1C. Most (57%) did not consider out-of-pocket costs in their decision making, and nearly half (42%) did not wish for their physician to consider such costs. However, respondents were more likely to agree that their physician, as opposed to themselves,

Table 1. Patient Demographic and Clinical Characteristics

Characteristic	% of Patients
Age, years	
Median	59
Range	22-84
Sex	
Female	63
Male	37
Time since diagnosis	
< 3 months	5
3-6 months	12
6-12 months	12
1-2 years	17
2-5 years	24
> 5 years	29
Cancer type	
Breast	36
GI	15
Genitourinary	16
Lung	10
Gynecologic	9
Other (lymphoma, melanoma, sarcoma)	13
Currently undergoing chemotherapy	
Yes	42
No	58
Ethnicity	
White	87
Black/African American	6
Asian	2.5
Other	4.5
Education	
Some high school or less	2
High school diploma or GED	18
Vocational degree or some college	18
College degree	27
Professional or graduate degree	35
Annual income, \$	
< 24,999	12
25,000-49,999	13
50,000-74,999	17
75,000-99,999	12
100,000-249,999	23
> 250,000	9
Employment status	
Full time	34
Part time	15
Unemployed	10
Retired	26
Disabled	9
Medical leave of absence	4

Continued on next column

Table 1. Patient Demographic and Clinical Characteristics (Continued)

Characteristic	% of Patients
Respondent has left job since diagnosis	
Yes	30
No	70
Family member has left job since diagnosis	
Yes	10
No	90
Respondent is primary wage earner in household	
Yes	46
No	50
Insurance coverage	
Medicare only	2
Medicare with supplemental	24
Private or employer based	65
Medicaid or Mass Health	6
Uninsured	2
Prescription drug coverage	
Yes	87
No	11
Stage at survey*	
Surveillance without active disease	34
Undergoing treatment for localized disease	14
Metastatic or recurrent disease	52

Abbreviation: GED, general equivalency diploma.

* Based on the 171 patients who allowed medical record review.

should consider out-of-pocket costs when making decisions about cancer care (34% v 24%; $P < .001$). Among those who considered their out-of-pocket costs, 70% also agreed that their physician should consider out-of-pocket costs when making medical decisions.

Similarly, a majority of respondents disagreed with having the health care costs of the country influence individual cancer management decisions. Among the sizable minority in favor of considering national costs, a greater number of respondents agreed that cost consideration should be the physician's responsibility rather than the patient's (26% v 17%, $P < .001$).

Associations With Communication Preferences Regarding Out-of-Pocket Costs

The only factor significantly associated with a desire to discuss out-of-pocket costs was current chemotherapy use (Appendix Table A1, online only). Participants actively being treated with chemotherapy at the time of survey administration were twice as likely to disagree with the statement, "I would like my doctor to talk with me about my out-of-pocket costs when he/she recommends a cancer test or treatment," as compared with those not actively undergoing chemotherapy (12% v 23%; $P = .035$). No other demographic factors were significantly associated with a communication preference, including: sex, ethnicity, education, income, employment status, and insurance status.

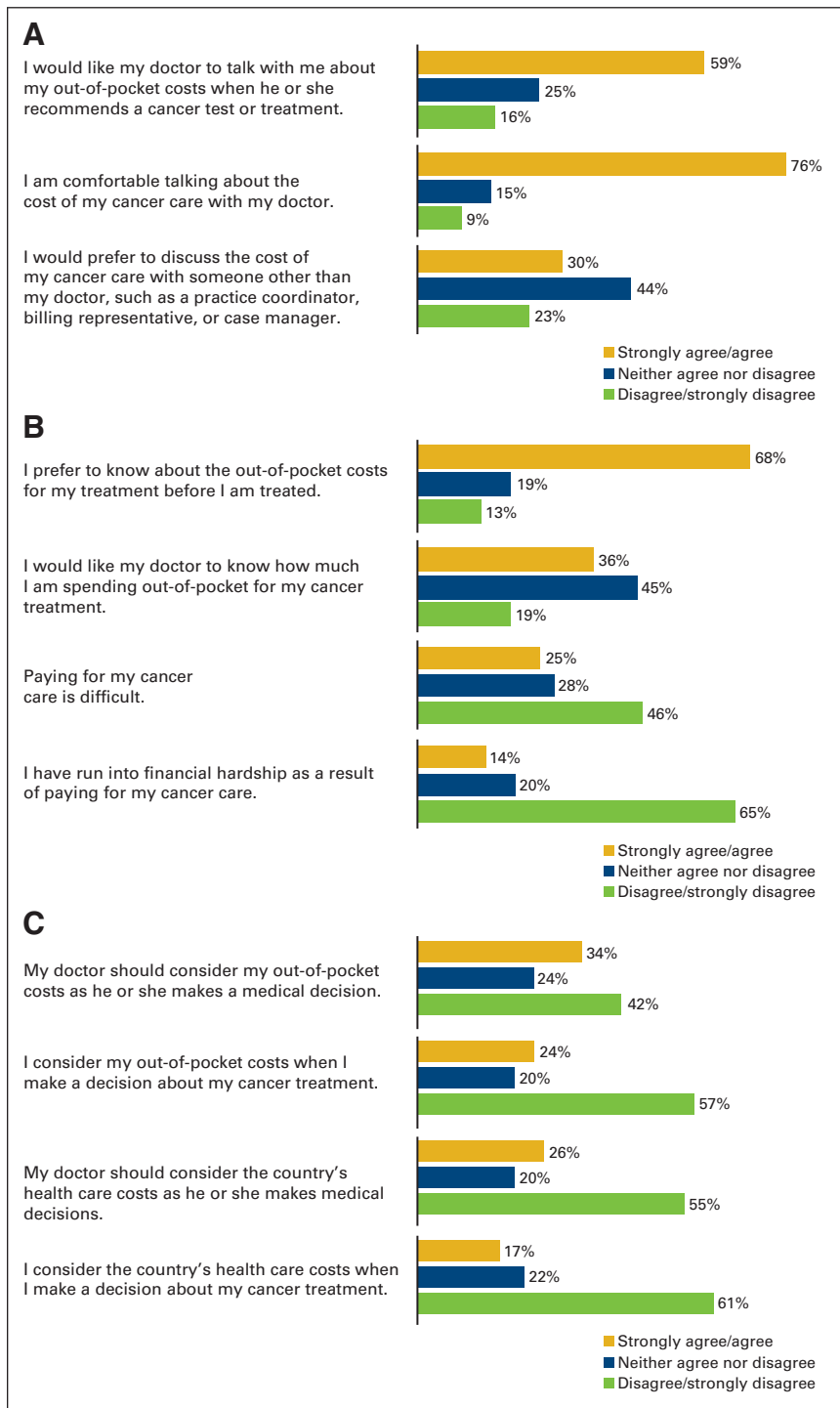


Figure 1. Responses regarding (A) communication preference, (B) cost burden, and (C) influence of cost on medical decision making.

Cancer-specific factors, including cancer type and stage, were also investigated. Of the 256 respondents, 171 agreed to a review of their medical record for disease staging and treatment information. Given the broad range of disease types within our sample and potentially conflicting treatment and survival implications of traditional TNM staging among different cancer types, we opted to categorize cancer stage as: localized disease, no evidence of disease, or metastatic/recurrent disease. Defined in this way, staging was not significantly associated with a communication preference about out-of-pocket costs.

Patients' perceptions about therapeutic goals, curative versus palliative, and their relation to out-of-pocket cost communication preferences were also investigated, and again no significant differences were identified.

Qualitative Responses

In the qualitative portion of the study, participants were asked to provide additional comments. Representative examples are presented in Table 2. Those in favor of cost discussions high-

Table 2. Qualitative Responses

Patients Who Do Want to Discuss Cost	Patients Who Do Not Want to Discuss Cost
"If/when physicians present options, they should recommend choices 1,2, and 3 based on best care first. Then compare costs with the patient and the risks/benefits of the differences. I may choose my grandchild's education or daughter's health over mine due to cost, but that is my choice."	"I don't think doctors have to be burdened with discussing health care costs with patients. All I want to discuss with my doctors is my health."
"I underwent IL-2 treatment and was shocked to learn of the cost from a nurse. I think more openness on these costs is important, not only from the point of view of containing health care costs, but also eliminating the stigma of secrecy on costs I believe the cost/benefit analysis must include the patient."	"Doctors should focus on care not cost. Single payer!"
"I often wonder about the costs of the tests, exams, etc. Sometimes I feel that tests are given that I don't really need. There may be places to save on health care costs. On the other hand, I am grateful for receiving good care I wouldn't mind discussing the costs with my physician and how best to save money."	"I trust my doctor's judgment and recommendation for treatment. I don't think certain tests or treatments would be ordered unless necessary, so I don't feel the system is abused."
"Knowing the cost of treatment is important, even if the insurance pays for most of it."	"Money should not dictate treatment."
"Hospitals should voluntarily know and disclose costs, even if all procedures are insured. Patients should control costs by being selective."	"I do not think it should be the doctor's responsibility to discuss care cost. That is asking too much from a physician. They can inform patients of relative cost, but more specifics should be handled separately."
"I feel people should know the cost of their treatment when they carry employer-based health insurance so that they are not so cavalier about costs to the health care system. Because we don't know, we are not active consumers. We do not pick and choose based on the pros and cons."	

Abbreviation: IL-2, interleukin-2.

light a desire for transparency and patient involvement. Those opposed to cost discussions expressed trust in their physician and a desire not to burden the physician.

Discussion

Despite recommendations for oncologists to engage their patients in cost discussions, no data exist regarding patient perspectives on cost communication in oncology. Understanding patient attitudes toward cost communication is critical for guiding conversations on this potentially charged topic. In a sample of patients with cancer seen at an academic oncology practice in Massachusetts, we found that a majority felt comfortable discussing out-of-pocket costs with their physician and would welcome financial discussions at the time of diagnosis and treatment recommendations. Patients in our sample demonstrated attitudes similar to those of primary care patients,⁹ and our data indicate that patients' comfort with this topic far exceeds that of oncologists. As recent surveys show, only a minority of oncologists (37%) report feeling comfortable having cost discussions with their patients.⁶ Our results should encourage oncologists to engage their patients in cost discussions, recognizing that a majority of patients would likely welcome out-of-pocket cost communication and would willingly participate.

Our data may also provide insight into patients' motivation for discussing cost. Most patients wanted to know about out-of-pocket costs at the time of treatment, but few acknowledged that cost would influence their personal medical decisions or wished for cost to influence their physician's decisions. Even in an environment of mandated health insurance in Massachusetts, one in four patients among our sample reported difficulty in paying for their cancer care, and nearly one in seven had fallen into financial hardship. Despite substantial financial hardship, a majority of patients in our sample did not want cost to influence medical decision making. Instead, patients' moti-

vation for discussing cost likely arises from a desire to be informed. Our data suggest that a patient's desire to understand treatment-associated out-of-pocket costs does not equate to a desire for cost to influence medical decisions, and most patients do not regard cost communication as an avenue for reducing health care spending.

In our study, most patients reported that their out-of-pocket expenses would not influence their decision making. However, a recently published survey of medical oncologists found that 84% make recommendations that are influenced by their patients' out-of-pocket costs,⁷ highlighting the discrepancies in how physicians and patients approach cost consideration and communication. Interestingly, our study found that those patients who agreed that cost should be considered in decision making were more likely to agree that the physician, as opposed to the patient, should consider such cost. This includes both out-of-pocket costs and costs to society. These data raise important questions about who should bear the burden of cost consideration in oncologic decisions. It is clear that some patients prefer to play a more passive role in medical decision making, and this may include financial considerations as well.¹⁵

Our data demonstrate that most patients want to discuss out-of-pocket costs with their oncologist. This, combined with the known financial burden encountered by many when paying for cancer care,¹⁶ underscores the importance of this topic and the critical need to address barriers to cost communication. Lack of time and knowledge present two major barriers to effective cost communication between physicians and patients.^{6,9,17} Results from this study should motivate oncologists to educate themselves about cancer care costs and encourage oncology organizations, such as the American Society of Clinical Oncology, to advance educational efforts in cost communication for their members.^{18,19} Conceptualizing the discussion about cost as a discussion about financial

toxicity may help guide some physicians, who are already skilled at counseling their patients on other potential treatment-related toxicities.

Most patients in our sample were amenable to discussing cost with a nonphysician member of the oncology team. Even among those patients who wanted to discuss their out-of-pocket costs with their physician, a full third preferred to hold such discussions with someone other than their physician. Such a financial expert could provide information on out-of-pocket expenses and potentially help patients and families identify resources for mitigating financial burden. This team member may be less threatening for the minority of patients who were opposed to discussing cost with their oncologist and may improve workflow in a busy clinical practice.

Discussions of cost, however, are intricately tied to discussions of prognosis and the perceived value of diagnostic and treatment modalities. Data have shown that patients' willingness to pay may reflect their perceived benefit of a treatment.²⁰ Ultimately, it is the oncologists' responsibility to educate patients on whether the intent of treatment is curative or palliative and the likelihood of attaining the stated goal. A substantial proportion of patients, however, may not recognize the gravity of their prognosis, and this can lead them to make different, often more costly, choices about treatment. In a recently published study of patients with metastatic non-small-cell lung cancer, most patients misunderstood that the intent of therapy was palliative, not curative.¹⁴ However, patients who held an accurate perception of their prognosis were less likely to receive intravenous chemotherapy near the end of life. Only in the context of honest communication about prognosis and the ability of a proposed treatment to provide benefit can patients make an informed decision about the value of a treatment and their own willingness to bear the expense.

One of the purported goals of advocating cost communication in oncology is to control health care spending. Interestingly, we found that the subset of patients who were likely to be driving health care costs up and facing the greatest expenses were less likely to want to discuss cost with their physician. Patients actively being treated with chemotherapy were less likely to want to speak with their physician about cost as compared with those not receiving chemotherapy. One could theorize that patients who are actively being treated for their cancer may fear they will not receive the most effective therapies if they admit to having financial concerns. They may also place higher value on their treatment and prioritize this over other financial considerations.²¹ Alternatively, patients being treated with chemotherapy may instead prioritize treatment response and symptom management over financial concerns during their physician visit.

To our knowledge, this study was the first of its kind to examine patients' attitudes toward cost communication in oncology. We recognize, however, that our study has several limitations. The study population was self-selected, and results may not reflect the attitudes of nonresponders. Because this was a self-administered questionnaire, there may have been varying interpretations of survey questions. Responses were collected in

only 3 weeks and may have been influenced by the political and economic environment at that time, because the study was conducted during vigorous debate regarding the Affordable Care Act of 2010. In addition, the majority of questions on the survey instrument inquired specifically about out-of-pocket costs. Thus, our results may not reflect patients' attitudes toward discussing overall cost of cancer care, which might include market cost of a given chemotherapy agent or costs covered by insurance.

The most important limitation of our study is that our results may not be generalizable to a broad population of patients with cancer. The survey was conducted at an academic medical center in the state of Massachusetts, where health insurance is mandated. Our sample was composed of a relatively affluent, highly educated, and predominantly female population, with more than one third of patients being treated for breast cancer. Nearly 30% of participants were more than 5 years out from their original diagnosis. In contrast, data from the US Census Bureau show the median US household income to be approximately \$50,303, with only 28% of Americans holding a college degree or higher.²² Men comprise 52% of all cancer diagnoses in the United States, with breast cancer representing 14% of all cancer diagnoses.²³ Although the 5-year relative survival rate for all cancer types reaches 68%, individual survival rates are heavily affected by both type of cancer and stage at diagnosis.²³ Thus, our sample likely differs from the overall US population of patients with cancer in important ways. Although we did not identify these demographic or cancer-specific factors to be associated with out-of-pocket cost communication preferences, it will be important to confirm our findings in different sample populations over more lengthy time periods.

In conclusion, we found that the majority of oncology patients within our sample felt comfortable with and wanted to discuss out-of-pocket costs related to cancer care with their physicians. Thus, further education and resources are needed to enable physicians to include cost communication in their oncology practice. Additionally, we found that a majority of oncology patients did not want cost to influence medical decision making, whereas the literature suggests that many oncologists do consider cost when making treatment recommendations. Given this divergence in viewpoints, further research is needed to evaluate how physician-patient communication about cost and the value of cancer care affect not only the overall cost of cancer care but also patient satisfaction and cancer outcomes.

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Appendix

Table A1. Distribution for Participants Responding to Statement: "I Would Like My Doctor to Talk With Me About My Out-of-Pocket Expenses When He or She Recommends a Cancer Test or Treatment."

Characteristic	Agree/Neutral (%)	Disagree (%)	P*
Sex			1.00
Female	84	16	
Male	83	17	
Time since diagnosis			.196
< 3 months	83	16	
3-6 months	80	20	
6-12 months	80	20	
1-2 years	74	26	
2-5 years	85	15	
> 5 years	91	9	
Currently undergoing chemotherapy			.035
Yes	77	23	
No	88	12	
Ethnicity			.073
White	85	15	
Black/African American	80	20	
Asian	100	0	
Education			.270
Some high school or less	60	40	
High school diploma or GED	88	12	
Vocational degree or some college	77	23	
College degree	88	12	
Professional or graduate degree	85	15	
Annual income, \$.544
< 24,999	83	17	
25,000-49,999	81	19	
50,000-74,999	86	14	
75,000-99,999	80	20	
100,000-249,999	91	9	
> 250,000	77	23	
Rather not say	92	8	
Employment status			.586
Full time	83	17	
Part time	87	13	
Unemployed	76	24	
Retired	89	11	
Disabled	77	23	
Medical leave of absence	80	20	
Respondent has left job since diagnosis			.338
Yes	81	19	
No	86	14	
Family member has left job since diagnosis			.776
Yes	87.5	12.5	
No	84	16	
Respondent is primary wage earner in household			1.00
Yes	84	16	
No	84	16	

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Table A1. Distribution for Participants Responding to Statement: "I Would Like My Doctor to Talk With Me About My Out-of-Pocket Expenses When He or She Recommends a Cancer Test or Treatment." (continued)

Characteristic	Agree/Neutral (%)	Disagree (%)	P*
Insurance coverage			.405
Medicare only	80	20	
Medicare with supplemental	86	14	
Private or employer based	84	16	
Medicaid or Mass Health	87	13	
Uninsured	50	50	
Prescription drug coverage			.401
Yes	85	15	
No	78	22	
Stage at survey†			.059
No active disease	91	9	
Localized disease	68	32	
Metastatic or recurrent disease	84	16	
Cancer type			.271
Breast	89	11	
Colon/rectal	76	24	
Esophageal/stomach	60	40	
Kidney	80	20	
Liver/gallbladder	100	0	
Lung	72	28	
Lymphoma	67	33	

Abbreviation: GED, general equivalency diploma.

* Fisher's exact test.

† Based on the 171 patients who allowed medical record review.