

Medical Oncologists' Views on Communicating With Patients About Chemotherapy Costs: A Pilot Survey

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ABSTRACT

Purpose

As chemotherapy costs escalate, financial concerns have become relevant for more cancer patients. Yet, little is known about how oncologists communicate with patients about coping with chemotherapy treatment costs.

Methods

To understand how medical oncologists view these issues, we developed a survey eliciting their attitudes and behaviors surrounding discussing costs of therapy in the context of treatment decision making. The survey was piloted at a national meeting and then mailed to a random sample of actively practicing 2005 American Society of Clinical Oncology members in the 50 United States. Survey items used a 5-point Likert scale designed to elicit oncologists' practices and attitudes regarding discussion of chemotherapy costs with patients. The first survey wave also included two clinical vignettes about hypothetical patients contemplating treatment with high-cost regimens.

Results

Of 530 mailed surveys, 167 were returned for an overall response rate of 31.5%. Most oncologists reported knowledge of their patients' financial well-being: 15% all of the time, 39% most of the time, 33% some of the time, and 13% rarely/none of the time. There was substantial variation in oncologists' attitudes toward discussing chemotherapy costs with patients: 42% did so always or most of the time, 32% sometimes did, and 26% rarely or never did. Most oncologists (80%) felt that it was important to be explicit about the impact of treatment choices on patients' finances. However, 20% maintained that costs play no role in clinical encounters, and 31% reported a high degree of discomfort in discussing costs with patients. Referral to support staff for these discussions was common. Only a few oncologists (16%) acknowledged omitting treatment options on the basis of their perceptions of patients' ability to afford treatment.

Conclusion

There is important heterogeneity in medical oncologists' attitudes toward discussing chemotherapy treatment costs with patients. Mismatch between physician and patient viewpoints has the potential to result in miscommunication and suboptimally informed treatment decisions.

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INTRODUCTION

The way that medical oncologists portray and communicate the trade-offs for particular chemotherapy regimens has tremendous influence on the treatment decisions that patients ultimately make. The financial cost of treatment is one factor in these decisions that may influence patient preferences. At present, very little is known about how medical oncologists broach the issue of cost when discussing treatment options with cancer patients. As the costs of chemotherapy skyrocket, such that even patients with good health insurance coverage have substantial copayments, the need to confront this thorny issue is becoming increasingly common.¹ Although

there is some literature about how patients discuss out-of-pocket costs in the context of outpatient medical practice,²⁻⁴ patients facing life-threatening illnesses and their providers may have different expectations and values regarding the role of economic considerations in treatment decision making.⁵

Medical oncologists face a conundrum about whether to confront the issue of costs. One approach is to avoid the issue of cost altogether and to focus exclusively on recommending treatments that provide clinical benefit irrespective of their costs, the patient's financial circumstances, or the impact of the treatment decision on other important life choices. This strategy appeals to physicians' desire to be equitable and to offer patients optimal treatment

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irrespective of socioeconomic status. The alternative approach involves consideration of how treatment choice will impact more globally on the patient's well-being and the resources available to cope with chronic life-threatening illness. For example, choices to receive expensive cancer treatment toward the end of life may hinder the ability to stop work, take a special vacation, hire domestic help, or fund children's education. Assumptions about financial security based on occupational status, race, dress, or place of residence are unreliable, and eliciting the detail necessary to understand patients' available resources and how treatment choices preferences for using those resources is time consuming. We sought to understand medical oncologists' attitudes toward discussing costs of chemotherapy with their patients as well as the frequency and circumstances in which they actually do so.

METHODS

Preliminary Interviews and Pilot Survey Development

Review of the literature, published studies, and existing instruments for understanding patient-physician communication identified no measure sets suitable for elicitation of physicians' attitudes toward discussing costs with patients.⁶⁻⁹ Previous studies have focused on out-of-pocket costs for prescription drugs and were not directed toward cancer patients or patients with life-threatening illnesses. Accordingly, open-ended questions, draft survey items, and hypothetical patient vignettes were reviewed with medical oncologists, 11 in academic practice at Memorial Sloan-Kettering Cancer Center, 17 in community practice, and 9 in academic practice attending the March 2006 meeting of the National Comprehensive Cancer Network. At each step, feedback was incorporated to identify important themes and to develop, refine, and clarify survey items and vignettes. For example, when asked whether they discussed the costs of chemotherapy with patients embarking on expensive regimens, some oncologists responded yes and then clarified that they did not engage in these discussions directly but rather delegated them to a practice manager. Thus, the need to specify whether discussion of costs involved direct patient-physician communication or, alternatively, if such interactions were relegated to a third party became apparent.

Pilot Survey Methods

The 2005 American Society of Clinical Oncology (ASCO) membership directory was used to identify a random sample of medical oncologists practicing in the 50 United States. Surgical, radiation, gynecologic, and pediatric oncologists were not included. Medical oncologists were included irrespective of board certification or years in practice. Subjects were sent a cover letter requesting participation in a survey about attitudes, beliefs, and practices regarding discussing the costs of chemotherapy with patients. Surveys were mailed in two waves. The first wave was mailed to 325 oncologists in May 2006 and included vignettes for hypothetical patients confronting decisions about expensive chemotherapy treatment in the setting of advanced cancer with limited life expectancy. A stamped return envelope was provided; but no reminders or compensation was provided to participants. In an effort to generate a larger sample size and to increase response rate, a second survey mailing with identical methodology except that it excluded the vignettes was sent to an additional group of 205 medical oncologists in June 2006.

Oncologists were asked to indicate the number of years they had been in practice and their practice setting (academic v community oncology v other/administration), but no other information including respondent gender and race was ascertained. Surveys were anonymized such that responses could not be linked back to a particular physician unless he or she chose to enclose a note or letter containing identifying information. Many respondents (n = 17) wrote detailed comments on their surveys in space left for free text feedback.

Analytic Strategy

The primary objectives were to generate pilot descriptive data about medical oncologists' communication behaviors with patients about costs of

chemotherapy treatment; and medical oncologists' views about whether cost considerations should play a role in making treatment recommendations to individual patients. Because this study was designed as an exploratory analysis and no hypothesis testing was planned or conducted, results were analyzed using simple descriptive statistics. We evaluated associations between responses using simple frequencies and evaluated the bivariate and multivariate interrelationships between survey response items using simple cross tabulations without adjustment for multiple comparisons or tests of significance.

Vignettes

Case vignettes were designed to elicit oncologists' approach to broaching the issue of costs in specific clinical circumstances. The first vignette asked oncologists to consider the case of a 69-year-old, middle-class retiree with newly diagnosed metastatic colon cancer to liver and lungs. Oncologists were asked to assume that the optimal regimen was fluorouracil, leucovorin, oxaliplatin, and bevacizumab and that the patient's out-of-pocket expenses and copays amounted to \$3,000 per month with anticipated duration of therapy of 5 months. The next vignette considered the same regimen for metastatic colon cancer to liver and lungs, but the patient was now a 59-year-old high school teacher who indicated that he wishes to continue working for as long as possible to ensure that his three teenage children will have money for their college tuition. The third vignette described a colon cancer patient who progressed on first- and second-line therapy and for whom cetuximab and irinotecan therapy are associated with a 2-month improvement in median survival and a \$3,000 per month out-of-pocket cost. For each vignette, oncologists were asked to identify their approach to discussing treatment options by selecting their preferred strategy for addressing costs in the context of therapeutic decision making from among four categoric options. Space was provided for comments or to indicate if none of the suggested response categories were reflective of behavior.

Survey Content

All versions of the survey contained 13 items with responses graded on 5-point Likert scales. Eight items asked medical oncologists about practices when communicating with patients about chemotherapy treatment. Five questions were intended to elicit oncologists' attitudes regarding whether they had an ethical obligation to either the patient or society to directly consider and address costs.

RESULTS

Cohort

Overall, 167 of 530 surveys were returned by mail, representing a response rate of 31.5%. Wave 1 was returned by 96 of 325 subjects to whom it was mailed, representing a response rate of 29.5%. Wave 2, which did not include the vignettes, was returned by 71 of 205 subjects for an only marginally better response rate of 34.6%. Respondents were 70% community oncologists; 23% academic oncologists, 2% were fellows; 3% were in administration, industry, or government service; and 2% did not specify. Because the surveys were anonymized such that a response could not be linked to a specific ASCO member, we do not know how the characteristics of respondents and nonrespondents compared. When asked to estimate the proportion of their time devoted to patient care, 77% of respondents said more than 75%, 17% said between 25% and 75%, 6% said less than 25%, and 0% omitted this question. The number of years in practice was less than 5 years for 15%, 5 to 15 years for 27%, more than 15 years for 56%, and unspecified for 2%.

Vignettes

Vignettes were completed by 95 of 96 physicians who responded to the first survey wave. Respondents varied considerably in their preferred approaches to communicating with patients about the costs of therapy. Of these, 18% would not explicitly address costs, 38%

would explicitly mention costs as part of a discussion about risks and benefits, 35% would extend this to include discussion of the impact of expensive therapy on the patient's overall well-being including mention of less costly alternatives, and 9% chose none of these options. Responses were essentially identical in the second vignette in which the patient alludes to financial concerns but does not address the issue of cost directly. In the final vignette, which describes cetuximab with irinotecan, the anticipated benefits of therapy are smaller. In this case, 2% of respondents indicated they would not discuss this treatment option at all, 12% would discuss the treatment but not explicitly discuss costs, 59% would explicitly discuss costs when mentioning the pros and cons of therapy, 20% would also discuss the impact of this choice on the patient's resources, and 7% wrote in other options. Several comments noted that less affluent patients paradoxically seemed to raise the issue of high treatment costs less than the more affluent. Several physicians explained their reluctance to broach cost issues on the basis of not wanting to be judged as discriminatory.

Survey Responses

Oncologists' responses to the structured survey items are shown in Table 1. Only 13% of oncologists reported rarely or never having a sense of their patients' financial well-being. These providers were neither more nor less likely to discuss costs with their patients than those practitioners who reported being attuned to their patients' economic circumstances.

Oncologists' comfort levels for discussing costs with their patients were widely distributed with just more than one third mostly comfortable, one third sometimes comfortable, and one third rarely or never comfortable. Irrespective of comfort level engaging in these discussions, 42% of oncologists usually, 32% sometimes, and 26% rarely or never engaged in them. Only 16% of survey respondents would omit discussion of regimens that they thought were economically inaccessible for a patient. Many respondents involved practice coordinators or case managers from insurance companies to handle these discussions.

When asked about specific circumstances that would lead them to initiate discussion with a patient about the costs of chemotherapy, 86% of all respondents said they discussed costs when the patient asks; 78%, when they know the patient is underinsured or has limited resources; 71%, when they think that cost might be a decisive factor in a treatment decision; and 69% when the treatment plan involves very expensive drugs. Respondents also noted circumstances that increased the likelihood of their initiating cost discussions: anticipated insurance company denial of coverage, hesitancy about effectiveness, the availability of pharmaceutical company assistance programs, off-label drug use, patient requests for drugs based on advertising, or availability of clinical trials.

The vast majority of oncologists (80%) agreed that it is important to be explicit with patients about the economic consequences of their treatment choices and similarly, 86% thought that oncologists have a responsibility to consider the impact of treatment decisions on patients' financial well-being. While 66% felt that oncologists should consider cost-effectiveness when making treatment recommendations, 19% disagreed or strongly disagreed (11% strongly disagreed). We used two items to ascertain oncologists' viewpoints about incorporating economic considerations into clinical recommendations. First, we asked whether the oncologists' role includes considerations of cost-effectiveness, and second, we asked whether they perceived a

Table 1. Medical Oncologists' Behaviors and Beliefs About Considering Costs in Chemotherapy Treatment Decision Making (N = 167)

| Survey Item | Response (%) | | |
|---|----------------------|----------------------------|----------------------------|
| | Always/Mostly | Sometimes | Rarely/Never |
| Perceptions | | | |
| I have a sense of my patients' financial well-being | 54 | 33 | 13 |
| Paying for cancer treatment is difficult for my patients | 37 | 52 | 11 |
| Costs influence my patients' decisions about treatment | 23 | 46 | 31 |
| Behaviors | | | |
| I am comfortable discussing costs of cancer treatment with patients | 37 | 32 | 31 |
| I discuss the costs of cancer treatment with my patients | 42 | 32 | 26 |
| I refer my patients to a third party such as a practice coordinator or billing representative | 46 | 30 | 24 |
| I refer my patients to a third party when recommending high-cost treatments | 63 | 19 | 18 |
| I omit discussion of very expensive cancer treatments when I know the cost will place great strain on my patients' resources | 16 | 30 | 54 |
| <hr/> | | | |
| | Strongly Agree/Agree | Neither Agree nor Disagree | Strongly Disagree/Disagree |
| Attitudes and philosophy | | | |
| It is important to be explicit with patients about the financial consequences of treatment options | 80 | 10 | 10 |
| Oncologists have a responsibility to consider the impact that treatment decisions may have on their patients' financial well-being | 86 | 8 | 6 |
| It is important for patients to understand the cost of their treatments even if they do not bear it directly themselves | 72 | 17 | 11 |
| Part of the oncologist's role when making recommendations is to consider cost-effectiveness | 66 | 15 | 19 |
| With marginally effective cancer treatments, oncologists have a responsibility to balance the patient's well-being with the use of societal resources | 60 | 21 | 19 |

responsibility to balance the patient's needs with concerns about the use of societal resources when recommending treatments with marginal efficacy. Responses to these two items were almost perfectly correlated. The same 19% of oncologists disagreed that concerns about costs should influence treatment recommendations. Only 11%

of oncologists disagreed with the statement that it is important for patients to be aware of the costs of their treatment even if they do not bear it themselves (Table 1).

Those oncologists who did not feel that oncologists have a responsibility to consider societal resources when recommending marginally effective treatments rarely discussed costs with their patients. In contrast, those who felt that use of societal resources was germane to these recommendations typically did discuss the costs of care with their patients (Table 2).

Responses of community and academic oncologists and oncologists in practice for longer than or fewer than 15 years were compared and no major differences or patterns were evident. For example, 47% of community oncologists discussed costs with their patients always or mostly, whereas 40% of academic oncologists reported doing so.

DISCUSSION

Rapid escalation of the costs of chemotherapy and the substantial out-of-pocket copays required even for adequately insured patients have created new challenges for medical oncologists. Yet, there is scarce information about how oncologists juggle the responsibility to forge a therapeutic alliance and recommend the best possible treatment with disclosure of the financial consequences of treatment for the patient. Almost no research has examined how oncologists cope with this tension, although there has recently been interest in determining the extent to which oncologists themselves are motivated by financial incentives.⁹ This pilot analysis was undertaken to gain a preliminary understanding of oncologists' communication behaviors as well as their beliefs about their roles.

Based on responses to vignettes and this pilot survey, it is clear that there is substantial variation in oncologists' beliefs. The vast majority recognized that it is important to be explicit with patients and a clear majority recognized that oncologists have a dual allegiance to the patient as well as to responsible use of societal resources. The problem of physician's dual allegiance to the individual and to society provoked intensive debate within the context of physician incentives in capitated managed care plans.¹⁰ Some have argued that both practically and ethically, physicians cannot incorporate cost considerations into individual treatment recommendations and that explicit thresholds must be established.¹¹ In contrast, others have maintained that cost considerations can be brought to the bedside in a way that will sustain trust among patients and the public.¹²

Comparing response patterns in simple bivariate analyses revealed a small group of oncologists—about one fifth of respon-

dents—who are consistently uncomfortable discussing costs, do not do so, and do not perceive that the oncologists' role encompasses consideration of cost-effectiveness. Specifically, the 19% of respondents who did not think the oncologists' role should balance patient well-being and use of societal resources also did not discuss costs with their patients. At the other end of the spectrum, approximately one third of respondents were relatively comfortable discussing costs, typically did so, and perceived that it is important for oncologists to consider individual patient's well-being as well as the judicious use of societal resources.

Prior research on physician communication about costs of care has focused primarily on out-of-pocket costs for prescription drugs. Alexander et al⁶⁻⁷ surveyed patients and their primary care physicians and found that both groups believe that discussion of out-of-pocket costs was important part of therapeutic decision making yet noted that these discussions were distinctly uncommon. From the patient perspective, barriers included uncertainty about whether the topic was appropriate, embarrassment, and the perception that the physician's time was limited. From the physician perspective, the primary barrier reported was lack of time. Physician discomfort, lack of solutions, lack of knowledge about the patient's individual circumstances, and uncertainty about whether introducing the topic of costs would be perceived by patients as a willingness to compromise on quality were also mentioned. Our results suggest that oncologists are similar to the primary care physicians surveyed by Alexander. While most providers recognize economic considerations as a legitimate aspect of therapeutic decision making, a substantially smaller proportion actually engage in these discussions.

In a more recent study, Nadler et al⁸ surveyed 90 academic medical oncologists in Boston about whether costs should factor into treatment recommendations. The majority agreed that patients should have access to effective treatment irrespective of costs (78%). While 81% agreed that out-of-pocket costs in general could influence chemotherapy treatment recommendations, only 30% agreed (and 59% disagreed) that costs of new cancer therapies had actually influenced their treatment recommendations.

Oncologists clearly recognize that in contrast to general internists who routinely confront the issue of cost when choosing lipid or anti-hypertensive therapy, cancer treatment recommendations are delivered in the context of life-threatening disease, which results in subordination of financial concerns.¹³ This insight also underscores the importance of scrutinizing communication styles particularly in circumstances where high economic costs need to be balanced against relatively modest gains in survival.

Oncology professional societies have not directly addressed the thorny issue of patient-physician communication about costs of care, and this topic is not a standard component of medical school or postgraduate training curricula.¹⁴ The primary reason for this is that most physician organizations focus on the broader issue of access to care and stake out the position that treatment should be widely available for all those for whom it is effective. Costly cancer chemotherapy with relatively modest benefits challenges this tenet. However, oncologists already grapple with competing ethical obligations in the context of investigational trials.¹⁵

Why else might a majority of respondents have indicated that economic considerations were legitimate, but yet a substantially smaller group actually discussed this information in the context of decision making? Since many respondents reported that their

Table 2. Comparison of Oncologists' Communication Behaviors and Beliefs About Their Roles in Considering Costs

| I Discuss the Costs of Cancer Treatment With My Patients | With Marginally Effective Treatments, Oncologists Have a Responsibility to Balance Patients' Well Being With the Use of Societal Resources (%) | | |
|--|--|----------------------------|----------------------------|
| | Strongly Agree/Agree | Neither Agree nor Disagree | Strongly Disagree/Disagree |
| Always/mostly | 36 | 6 | 0 |
| Sometimes | 23 | 7 | 2 |
| Rarely/never | 1 | 8 | 17 |

patients struggled with the costs of chemotherapy, it is implausible that this issue was avoided because of patients' relative affluence. At one level, the survey suggests that oncologists typically triage cost discussions to third parties and feel ill-equipped to advise patients without having immediate answers to what is and is not covered by insurance. In this manner, treatment decisions cannot be considered fully informed because neither patient nor physician typically understands the economic consequences of treatment. In qualitative interviews oncologists noted that by referring discussion of costs to an office practice manager, it was more difficult for patients to later reopen discussion about lower-cost treatment alternatives. Although the survey did not explore attitudes toward and use of pharmaceutical-sponsored patient assistance programs, qualitative responses and pilot interviews indicated that the paperwork and time required to access these programs are impediments to use.¹⁶

The Physician Charter on Medical Professionalism, a project led by directors of the American Board of Internal Medicine sets forth three fundamental principles that form the ethical underpinning of physician behavior in the 21st century.¹⁷ These principles are the primacy of patient welfare, patient autonomy, and social justice. The principle of social justice calls for physicians to promote justice in the health care system, including the equitable distribution of resources and elimination of discrimination. Yet, discussing chemotherapy costs with patients may thwart adherence to the principle of social justice if it necessitates variation in treatment decisions based on economic status. In contrast, ignoring issues such as the capacity of the patient to cope with the financial ramifications of treatment necessitates conflict with another core principle—the centrality of patient autonomy. Conversations about chemotherapy costs are so especially difficult because they force physicians to confront situations where these ethical principles conflict. As one oncologist put it, “If a treatment works, it should be available to those who need it; if it doesn't, we shouldn't really be recommending it for anyone. These issues

shouldn't really be in our hands.” Oncologists emphasized that cancer medicine is also distinctly different from specialty care, such as plastic surgery, where patients fully expect costs to play a role in weighing treatment options.

This pilot study has important shortcomings. While not atypical for brief uncompensated physician surveys, the 30% response rate is low and means that the viewpoints of respondents described here cannot be assumed to represent the oncology community more broadly. Because this study had no link to patient information, it was not possible to obtain patient perspectives on communication about costs during actual clinical encounters.

Although neither this survey nor prior work¹⁸ is of sufficient scope of magnitude to fully evaluate these complex issues, it does portray the tension oncologists feel about this topic and the disconnect between beliefs about what their roles should encompass and their actual communication patterns. Further research is needed to determine whether these results were obtained because of different interpretations of the survey questions or alternatively because there is true heterogeneity among professionals. Presuming that the variation is real, efforts to define the parameters of ethical professional behavior in the context of cancer treatment decision making are warranted. ASCO as the leading professional society might take the lead by convening a workshop to assemble ethicists, clinician educators, and patient leaders to develop and identify professional standards and strategies for coping with this challenge.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The authors indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

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