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Patient and oncologist discussions about cancer care costs

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Abstract

Purpose—Patient out of pocket costs are higher for cancer care than for any other health care sector. Oncologist-patient discussions of costs are not well understood. We conducted an exploratory interview study to examine the frequency, patterns, attitudes, and preferences of both patients and providers on discussion of treatment costs.

Methods—We conducted semi-structured telephone interviews with oncology clinicians and people receiving chemotherapy at a large nonprofit health system. Multiple investigators conducted thematic analysis using modified content analysis, grounded theory, and interaction analysis methods.

Results—Patient themes included the relevance of cost to their experience, preference for the doctor to be the starting point of cost discussions, but relative infrequency of discussions with doctors or other care team member. Provider themes were an emphasis on clinical benefit above costs, conviction that cost-related decisions should rest with patients, and lack of access to treatment costs. Interest in discussing costs and barriers accessing cost information were common themes from both patients and providers.

Conclusions—Doctors and patients want to discuss treatment costs but lack access to them. These data support growing evidence for a provider role in discussions of cost during cancer treatment planning.

Appropriate keywords

Interview; qualitative; treatment cost; cancer; patient

Introduction

Medical bills are the leading cause of personal bankruptcy in the United States, and Americans with cancer are disproportionately burdened by high out-of-pocket expenditures [1]. Two million people with cancer may forgo needed care because of cost [2] and 84% of US oncologists report that patient out-of-pocket costs have influenced their treatment recommendations [3].

Despite the potential impact of cancer treatment costs on patients' financial security and treatment options, little is known about either patient or physician practices on communicating treatment costs. One study suggests patients rarely initiate cost discussions [4] and only 43% of physicians report frequent cost discussions with patients [3,5]. In a

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survey of American Society of Clinical Oncology members, 54% reported knowing their patients' financial status all or most of the time, however, reports on discussions of treatment costs with patients vary considerably [6-8]. While physicians are concerned about patients' costs they might not be equipped to discuss them [9,10]. A better understanding of the needs and preferences of patients for treatment cost information could assist clinicians and healthcare systems to improve communication, and possibly clinical decision making.

We conducted an exploratory interview study with oncologists and people receiving chemotherapy for cancer. Our objectives were to learn how patients and doctors communicate about the cost of cancer care and identify unmet needs from both perspectives.

Methods

Study sample

This study was conducted at Group Health Cooperative, a nonprofit integrated health care system serving more than 600,000 members in Washington State. The Group Health Institutional Review Board approved the study protocol.

We approached all 14 physicians and physicians' assistants employed or contracted to provide oncology services to Group Health members via an internal email with a study description from the principal investigator (NH). Participating clinicians provided verbal informed consent and received no monetary incentive.

We identified a gender-stratified sample of people receiving cancer care at outpatient oncology clinics in the first six months of 2010 via administrative data. Inclusion criteria included people with a first incident, invasive cancer in the previous five years, age ≥ 30 , English-speaking, and received IV or oral cancer chemotherapy in the previous 9-12 months. Exclusion criteria included having taken only hormonal therapies (e.g., tamoxifen), in situ or benign neoplasm, being in hospice care, or a recent hospital stay >3 days long. We contacted eligible people by mail, including a study information sheet and opportunity to opt out, and then conducted a follow-up phone call to confirm eligibility. People agreeing to participate provided verbal informed consent and received a \$30 incentive. Two investigators (NH, LT) conducted telephone interviews during autumn 2011; all were audio recorded and transcribed.

We did not access any provider-level practice pattern data or patient medical records and did not recruit or analyze patients and providers as pairs.

To develop our interview guides we drew from the theory of reasoned action and theory of planned behaviors, the Charles model of shared decision-making, and published literature [11-13]. The provider guide had five semi-structured questions with probes to elicit frequency, patterns, and comfort of cost discussions; the impact of cost on practice; attitudes about cost discussions and the role of cost in care; and barriers and supports to optimal cost discussions. The patient interview guide had six semi-structured questions with probes to elicit patient experience with treatment costs; the content of any discussions with their provider and care team; attitudes about care costs; decisional control preference; and preferences, barriers and supports for optimal cost discussions. We collected demographic (without race/ethnicity), physician practice patterns and patient health insurance information.

The investigator team independently open-coded a random sample of provider and patient transcripts and created a codebook from common textual elements. All transcripts were then coded by a primary and a secondary coder (NH, ETL for the patient interviews, NH, LT for

the provider interviews). Any disagreements were resolved by team consensus. We used Atlas.ti Version 6 software (Berlin, Germany).

For thematic analysis, we used a combination of content analysis—counting frequencies of various constructs to identify the relative weight given to each—and constant comparative methods modified from grounded theory to build emerging themes from the codebooks and identify exemplar quotes [14,15]. We also conducted modified interaction analysis to compare the experiences, beliefs, and actions reported in the two samples [16].

Results

We approached 14 oncology care providers and interviewed 11 (Table 1). Average time in practice was 16 years; two were contracted providers and reported concurrent work in other practice models such as fee for service. We were unable to reach one provider and two did not have time to participate. We analyzed 22 patient interviews. From two consecutive mailings totaling 150 invitations, we screened 85 patients. Of those, 42 consented, of which 28 met our eligibility criteria and 27 completed interviews. We later excluded 5 interviews (all female) for reporting hormonal therapy only (online appendix).

Our thematic analysis suggested five themes shared between the two samples: cost is highly relevant to the patient experience; that it is secondary to clinical benefit; physicians are the preferred starting point for discussing costs; cost decisions should rest with patients; and both doctors and patients are insulated from treatment costs (Table 3).

Cost is relevant to patient experience

More than half of patients reported financial concerns about treatment; four (18%) reported financial assistance for treatment.

Five patients (23%) reported discussing costs with their doctor, while eight (36%) reported any cost discussion, including informal, with a pharmacist, nurse, or social worker. No patients reported a provider-initiated discussion of cost, and seven (32%) reported they brought up cost with the team.

Patient: There was no discussion at all about the costs of anything, of the treatment at all...Cost was never really brought up to our attention.

Clinician: Unless we bring it up, I suspect that we're hearing a lot less about costs and affordability from patients than we should be because this is not an issue that patients bring up a lot.

More than half of clinicians reported that patients initiated cost discussions; six (27%) reported that they initiated discussions, and several assumed that patients had adequate coverage. Clinician-reported frequency of doctor-patient cost discussions varied from 5% to 66%. Several clinicians noted an increasing trend in their practice of cost-related discussions.

The most common patient-reported source of treatment cost information was insurance or billing documents, nearly always after treatment was received. Nearly 60% of patients reported that their doctor was their preferred starting point for discussing treatment costs; only 32% said they preferred to learn about costs from their insurer. A minority of patients felt that doctors should not be concerned with costs (9%).

The most common source of cost information for clinicians was a colleague. More than one-quarter said they learned about costs from their patients, most often when a patient brought in a bill or explanation of benefit. Doctors and patients reported that cost-share or out-of-

pocket costs were the main source of patient cost concerns and reported patient concern about the total or societal costs of cancer treatment (Table 2). Decisions about generic vs. brand medications; injection vs. oral; biologics or oral chemotherapy; advanced imaging; bone marrow transplant; and ancillary care such as antiemetics or durable medical equipment were cited as cost issues. Clinicians mentioned test timing (e.g., before the end of the insurance plan year), and palliative care as patient concerns.

Participants also mentioned costs peripheral to treatment decision-making, including disability coverage, parking, nutritional supplements, the cumulative burden of cancer costs, and hospitalization and emergency services.

Cost is secondary to clinical benefit

Participants reflected a clear belief that clinical benefit should be at the forefront of any discussion of care costs. It was clear that arranging patient financial assistance when required was both a priority and an obligation.

Patient: I said, I have no prescription coverage. And he said, You have to have those shots. And I said, Well forget it. So he just said, Well let's go over to the oncology department and let's see what we can do because you've got to get them.

Clinician: I don't consider [cost]...I don't know detailed information regarding how much, what's co-payment. But I don't let that affect me myself. I just base it on the best evidence in my recommendation. If we have some problem with financial difficulty then we try to solve it.

Physicians are preferred starting point of cost discussions

Many people felt that the doctor, as the most clinically knowledgeable, should initiate or triage cost discussions, especially related to treatment choice. However, many people also felt that clinician access to or knowledge of patient costs is limited:

Patient: [Doctors] are in a position to understand or be aware of what's out there. Well maybe you could do this, or there's this happening over here, you can do that if this is too expensive, or kind of options. Because when I talked to the business office, they don't know anything about medicine.

Patient: I don't think my oncologist probably is aware of all [costs]. I don't know how they can be. It's so hard to keep up on the latest treatment things for every different kind of cancer or whatever. If somebody started throwing numbers at them I don't know how they could keep anything straight.

Both doctors and patients are insulated from costs

Providers almost unanimously reported unwanted insulation from treatment costs. Perceived sources of this insulation included the culture of medical training and cultural taboos against doctors knowing costs. Several mentioned that details of a patient's insurance coverage are not readily accessible during clinical encounters. One clinician called the gap between prescribed treatments and individual patient coverage "a black hole."

More than 90% of clinicians said that costs should be more readily available, either through an electronic source or the care team, such as financial counselors or social workers.

Clinician: We need a way to access the costs ourselves and what the patient's coverage is, that we could do it online without having to be put on hold to speak to a pharmacy technician would make it a lot faster. ...Is the patient really covered or not for this expensive drug?

Patients also expressed confusion and dissatisfaction at limited access to the cost of their care, saying that such insulation would not happen with purchases such as cars or veterinary care. Some said knowledge might have affected their choices.

Patient: If I had known [the medication] cost that much I probably would have said, Heck, it's really not worth that...it was not a big enough problem to have wasted that many health care dollars on. Especially when they were mine [laughter].

Others simply wanted to know their cost share before treatment began, for expense planning rather than as a part of treatment selection. One patient said: "How do patients know that this drug doesn't cost your \$60 co-pay? It costs \$6,000, and you may have to pay that." Another said:

Patient: I had already spent \$1,200 and almost \$1,300 out of pocket for drugs. Now I get a hospital bill for another \$1,400. I mean how many people have \$300 a month to throw at the wall for that kind of stuff, unplanned, unexpected?

Many patients recognized a potential role of costs in individual decision-making.

Patient: It doesn't hurt the treatment or anything like that, it just is kind of an exchange of information that patient and team should have. Because of the dollar amounts involved in health insurance now, I just think that's fair. Everybody needs to kind of be on the same page.

Cost-related decisions should rest with individual patients

Although a minor focus of our interview guide, clinicians reflected at length on the physician's role in treatment costs. Although nearly all wished that costs were more accessible, many voiced a belief that societal decisions about cost of health care should be separate from an individual doctor making clinical recommendations for a given patient.

Clinician: It would be nice if [cost] is a topic in congressional discussions...to get it out there on the table and make it clear that we are going to talk about this ...I think an organization could do a lot towards just kind of talking about it so it's not taboo to talk about it...We should be more upfront about the fact that we can bankrupt the country with medical costs.

Many clinicians also felt strongly that cost information should be shared with a patient, rather than making clinical recommendations based on cost without patient input.

Clinician: It doesn't matter how much you talk and who you talk to, you're still putting a value on someone's life, and who am I to do that?...I can put a value on my life if I want to, but how can I do that with someone else? I don't know if anyone can ever be comfortable with that.

Clinician: I think there's a segment of patients who start to make philosophical decisions based on the family and the financial needs of the family. It's kind of common... say an older guy who says, You know, I don't want to do all this and die from this disease anyway, then leave my family bankrupt.

A minority of patients and clinicians voiced comfort with the "status quo" - that costs do not enter the doctor-patient interaction. One patient said, "I was just not ready to face any of those [cost] things that first couple of months."

Discussion

We conducted an exploratory interview study to understand how oncologists and patients communicate about treatment costs. Our results suggest that cost is relevant to patients and

that doctor-patient discussion of treatment costs is acceptable and relevant to patient experience. Many patients wanted to know their total cost-share before embarking on a treatment episode and expressed a clear preference for the physician to be part of the discussion even if cost was not part of their decision. However, timely access to total costs and patient cost-shares limited cost discussions and likely leads to many missed opportunities to discuss cost with interested patients. Both doctors and patients are insulated from the cost of treatment at the point of care, and both desire more transparency around costs.

This work brings a unique perspective from both patients and physicians in the same time period and the same health care setting. Our work is consistent with other findings suggesting the magnitude of financial morbidity on people with cancer and other serious illnesses [17,18], and the stress associated with dealing with insurance and cost issues, including lack of clear explanation of costs at the time of treatment choice [19]. Consistent with other studies [3,5-8], relatively few doctors or patients initiated cost discussions, suggesting missed opportunities for discussion between clinicians and interested patients. Our work also supports research suggesting that while not all patients are comfortable discussing treatment costs, the comfort of those who are may surpass that of oncologists' [20].

We began this study hoping to identify intervention points where we could support communication around costs. Our study suggests that system-level changes to improve price transparency could be a first step in meaningful cost communication. Currently, the onus of finding price information lies with individual doctors who practice under tight time constraint and cannot access a patient's insurance coverage, or individual patients, who might lack clinical knowledge to explore alternatives. Without support or processes for finding costs, patients, doctors, and care teams face inefficient, time-consuming, and error-prone searches for information that may prove prohibitive.

The American Society of Clinical Oncology asserts that discussion of cost is part of high-quality cancer care [21]. Not surprisingly, our work shows that patients consider cost in the context of their lives beyond a given episode of cancer care. Discussion of cost of care may be a way to recognize a patient as a "whole person," in keeping with models of patient-centered care [13,22-27]. Our work offers an oncologist perspective to the growing clinician voice that willingness to discuss costs is consistent with patient-centered care [28,29] and may be an ethical imperative [30,31]. Cost-consciousness is increasingly included as a competency of medical training [32,33].

Our work also suggests system-level supports that can facilitate communication between physicians and patients. A recent Institute of Medicine paper suggests that an attribute of a "health-literate" health care system is clear communication about what health plans cover and what individuals will have to pay for services before the service is given and at the point of care [34]. Transparency about both outcomes and costs should be a "hallmark" of a learning health care system [35]. However, early efforts aimed at implementing or measuring the impact of cost or price transparency have focused on health plan or provider selection with mixed results [36]. Personalized, patient-meaningful cost information at the point of care may hold more promise for impacting the patient experience and health outcomes [37-39].

A limitation of our work is the low response rate from our patient sample. However, our study represents a range of ages and socioeconomic status, cancer type and stage, and opinions on the role of cost in medical care. Future work can establish the distribution of attitudes on cost and in different populations. Also, we explored the experience of doctors

and patients within a single organization and our results are not necessarily representative beyond our organization. However, few health care organizations facilitate access to costs to doctors or patients at the point of care, so our data is likely relevant to other health care settings. Also, the role of cost in integrated care systems is understudied and unique considering evidence for the impact of financial incentives on physician behavior [40].

Our data suggest that doctors and patients are willing and able to have open communication about treatment costs but are limited by lack of timely access to cost information. How to best make costs available to physicians, their teams, and patients at the point of care is an important area of future research, as is how it affects decision making, patient satisfaction, outcomes and costs. These preliminary qualitative data add to a growing body of evidence suggesting patient demand for discussing treatment costs at the point of care; physician education and access to treatment costs may improve patient education and support initiatives.

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Table 1
Sample demographics

	Patients	Clinicians
Total sample	22	11
Female	32%	45%
Age/years in practice: mean (range)	63.2 (43-79)	15.5 (4-32)
Interview length: minutes (range)	31 (13-59)	32 (11-54)
Contract provider	--	2/11 (18%)
MD oncologist	--	10/11 (91%)
Married	77%	--
Household income above \$50,000	77%	--
Some college or more	72%	--
Insured	100%	--
Years since diagnosis: mean (range)	2.8 (1-6)	--
Treated for breast, prostate, colorectal cancers or Leukemia	68%	--
Cancer stage III or IV	45%	--
Receiving oral agents (self-report)	32%	--

Table 2
Content analysis

	Patients ^a (n=22)	Clinicians (n=11)
	22	11
Received financial assistance	18.2%	--
Financial concerns related to treatment	54.5%	--
Cost discussion (patient - doctor)	22.7%	5% - 66% of patients
Cost discussion (patient - care team)	36.4%	--
Who brings up cost		
No one	59.1%	--
Patient	31.8%	54.5%
Doctor	0.0%	27.3%
Assumed adequate patient coverage	--	36.4%
Where do you learn about cost?		
Insurer (bills, EOBs, customer service)	36.4%	--
At pharmacy/pill bottles	18.2%	--
Doctor	4.5%	--
Clinic team (nurses, social workers, pharmacist)	9.1%	36.4%--
Patients	--	27.3%
Organizational resources (e.g. customer service)	--	18.2%
External resources (e.g. pharmacy websites)	--	9.1%
Where do you prefer to learn about costs?		
Doctor	59.1%	--
Care team/organization	4.5%	36.4%
Insurer	31.8%	--
Doctors shouldn't know about costs	9.1%	18.1%
Doctors should have more/easier access to	--	90.9%
Doctors have limited knowledge	22.7%	36.4%

^aNumbers do not sum to 100%, reflecting the frequency of mentions in open-ended interviews.

-- denotes a construct not coded in the sample

EOB, explanation of benefits

Table 3
Thematic analysis

Theme	Description
Cost is relevant to patient experience	May or may not affect therapeutic choices Cumulative financial burden is significant
Cost is secondary to clinical benefit	Financial assistance a team priority when needed Supportive/ancillary care may be more preference-sensitive with respect to cost (e.g., antiemetics; durable medical equipment; colony stimulating factors) than therapeutic agent
Physicians are preferred starting point of cost discussions	Physicians are uniquely equipped to discuss alternatives Other team members, insurer can facilitate assistance once a plan is reached
Cost-related decisions should rest with individual patient	Some patients prefer not to discuss cost at all May suggest a shared decision-making framework for some decisions Physician preference not to be the gatekeeper of cost information – should share all options with patients
Both doctors and patients are insulated from costs	Patient preference to know cost-share at time of treatment decision Physician preference to help patient estimate financial burden