



## A Touchy Subject: Can Physicians Improve Value by Discussing Costs and Clinical Benefits With Patients?

DANA S. WOLLINS,<sup>a</sup> S. YOUSUF ZAFAR<sup>b</sup>

<sup>a</sup>American Society of Clinical Oncology, Alexandria, Virginia; <sup>b</sup>Duke Cancer Institute, Sanford School of Public Policy, Duke University, Durham, North Carolina

*Disclosures of potential conflicts of interest may be found at the end of this article.*

Over the last decade, the cost of health care—and cancer care in particular—has risen dramatically [1, 2]. Increasingly, these costs are being passed on to patients in the form of cost sharing, which can have a catastrophic effect on the financial well-being of patients and their families [3, 4]. This “financial toxicity” of cancer treatment has been shown to impact patients’ finances, leading to nonadherence to prescribed treatment, dose adjustments, and skipping appointments [5]. As a result, the Institute of Medicine, the American Society of Clinical Oncology, and others have recommended that patients be clearly informed of costs as part of delivering high-quality cancer care [6, 7].

Although a growing body of evidence suggests that some patients struggle with treatment-related financial burden, until recently, little work has been done to identify effective ways of introducing cost into physician-patient discussions, or to place this information within the overall context of value. Value is now a topic of intense interest among patients, clinicians, payers, and policy makers, and it has been defined as a measure of outcomes relative to costs [8]. The patient perspective, however, is of critical importance in defining value. Because perception of value is so individualized, discussions with patients must include an assessment of patient needs, goals, and preferences. Including cost-benefit discussion in the decision-making process has the potential to both improve outcomes and decrease costs, thereby increasing the value of care delivered.

As prices continue to rise in the setting of greater cost-sharing, continuing with the model of prescribing treatment without discussing value is unsustainable. Policy interventions like price transparency legislation and reimbursement reform are important, but they take time to implement. A more immediate solution might be to focus on the patient-provider interaction as a means to improve value in cancer care. To determine whether the patient-provider interaction around cost is a reasonable area on which to focus for intervention development, we must first define a cost discussion, determine the benefit of those discussions, and describe the path forward in terms of research and intervention development.

### DEFINING THE COST DISCUSSION

Before determining whether a cost discussion between patient and provider is beneficial, we should first determine what composes a discussion of health-care costs. The definition of the term “health-care costs” varies by perspective when used by policy makers, the media, or patients. Policy makers often refer to costs in terms of governmental spending on health care, whereas health-care providers or payers are usually referring to the costs of providing care to patients. In considering what costs matter to patients, out-of-pocket expenses are likely to be top of mind for the individual. These costs include not only the direct costs of receiving medical care, but also the nonmedical costs involved during treatment, such as transportation, childcare expenses, and time off work. However, when costs escalate, the burden is experienced by society as a whole, and when health-care premiums rise in response, the individual’s pocketbook is affected as well. Hence, some have called for physicians to practice better financial stewardship of our limited resources when making medical decisions [9, 10]. Studies suggest most patients are not interested in discussing societal value when making treatment decisions [11]. With respect to individual patients’ perception of value from treatment, although many patients want to discuss costs, not all do [12]. Furthermore, the evidence suggests that some patients who want to discuss costs might still prioritize clinical benefit over cost [13].

Limited evidence exists as to the extent or quality of cost discussions between oncologists and patients. The incidence and quality of discussions have been studied in three ways: survey-based studies that query patients and/or providers about their desire to have cost discussions; survey-based studies that ask patients and/or providers to recall whether they have discussed costs with their oncologist; and studies of audio-recorded conversations between patients and providers. A great deal of variation exists in the degree to which patients report desire to have cost discussions, ranging from approximately 50% to nearly 100% of surveyed patients with cancer [11, 12, 14]. Similarly, studies based on recall suggest variation in the extent to which patients report discussing their costs with oncologists. Those estimates of cost discussion

Correspondence: S. Yousuf Zafar, M.D., Duke University Medical Center 2715, 2424 Erwin Road, Suite 602, Duke Cancer Institute, Durham, North Carolina 27705, USA. Telephone: 919-684-0138; E-Mail: [yousuf.zafar@duke.edu](mailto:yousuf.zafar@duke.edu) Received May 20, 2016; accepted for publication August 4, 2016; published Online First on August 22, 2016. ©AlphaMed Press 1083-7159/2016/\$20.00/0 <http://dx.doi.org/10.1634/theoncologist.2016-0207>

frequency vary widely, from as low as 14% of patients discussing their health-care spending with physicians to as high as 44% of patients discussing their health-care expenses in a single year [11, 15–17]. The heterogeneity in estimates may be, in part, a result of differences in study design, with survey-based studies subject to recall bias. Studies that rely on analyzing recorded conversations between physicians and patients report that 30% of patient-physician interactions include cost conversations [18].

Why are discussions about patient costs not occurring more frequently? Oncologists report multiple barriers to having effective cost discussions with their patients. Studies suggest that oncologists might avoid cost discussions because they are unprepared for those discussions [19]. In other words, oncologists do not know how much the treatment they prescribe will cost to any given patient, and few believe they have access to adequate resources to discuss costs [20]. With lack of transparency in health systems' pricing, and with per-patient variation in insurance coverage, tracking costs for patients is challenging, if not impossible. However, some oncologists do not believe that cost should play a role in discussions with patients, regardless of availability of cost data. Schrag et al. found that 20% of oncologists believed that costs play no role in clinical encounters [19]. Importantly, this study did not clarify whether the respondents were referring to societal cost discussion rather than a discussion of potential financial harm to the patient as a result of treatment. Patients also report a wide variety of barriers to having effective cost discussions with their oncologists. Those barriers include patients' own discomfort, insufficient time, a belief that their physician cannot reduce their costs, and concerns about the impact of cost discussions on quality of care [12].

Although little is known about the incidence of cost discussions, even less is known about whether there is an ideal time to have the discussion. An emotionally charged first visit with an oncologist might not be the most appropriate time for a cost discussion. However, common sense dictates that if a conversation about cost is helpful, it will likely be most helpful earlier in the course of care. Social workers and financial counselors are better able to provide financial assistance to patients before the debt is incurred rather than after [21]. In addition, these discussions must be tailored to individuals' literacy levels and personal circumstances. As well, these discussions should occur throughout the treatment period—particularly at times of treatment change—and throughout the cancer care continuum. After completion of treatment, cancer survivors are also at risk for experiencing financial burden [22, 23], suggesting that assessments for financial burden should continue into survivorship.

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### CAN COST DISCUSSIONS IMPROVE CARE AND INCREASE VALUE?

Although there have been a number of studies assessing physicians' and patients' attitudes and perceptions of discussing cost and individual value as a hypothetical construct, few studies have investigated the effect of these cost discussions. In a study of 1,755 recorded patient-physician conversations, Hunter et al. found that 22% of cost-reducing strategies discussed involved switching to lower-cost therapies [18]. Twenty-three percent of the time, physicians discussed

reducing out-of-pocket costs by changing the timing, source, or location of care [18]. Of note, this study was limited in that these strategies were recorded, but there was no follow-up to determine whether the strategies were instituted or whether they reduced costs for patients. This study also identified areas of potential improvement in patient-physician cost conversations. Two broad categories of physician behaviors were identified that led to missed opportunities to reduce out-of-pocket expenses. These behaviors included failing to recognize patients' implicit cues about financial burden, thereby dismissing concerns before exploring whether it is possible to reduce financial burden, or distracting from patients' concerns by expressing frustration with the system [24]. A study of 300 cancer patients found that 56 (19%) reported talking to their doctors about costs [12]. Of these patients who had a cost discussion, 32 (57%) reported lower out-of-pocket costs as a result of the cost discussion. Methods of cost reduction included physician referral of the patient to a financial assistance program (53%), the physician's advocacy for the patient or facilitation of 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 physician visits (6%). Although these results were based on a small sample, they suggest that cost discussions might help lower patients' financial burden without changing care in the majority of cases.

Beyond a handful of studies like these, very little evidence exists regarding how cost discussions between patients and providers impact patient care in general or financial toxicity in particular. Yet, very little harm likely results from these discussions. Kelly et al. assessed patient satisfaction after the cost of chemotherapy was introduced into the doctor-patient relationship [25]. Chemotherapy and targeted-therapy costs were provided to the patient by their oncologist during the consultation, using an Internet-based decision-support platform. Results showed that greater than 80% of respondents reported that it is "quite important" or "extremely important" for them to know what they will be personally responsible for paying. In addition, the majority of patients (81.2%) reported that they felt no negative feelings or conflicts (graded 1-2 on 10-point Likert scale) when they discussed cost of treatments with their oncologist. These conversations do not take a great deal of time; the median duration of a cost conversation is approximately 1 minute [18]. With little harm, an initial signal of benefit might be sufficient to encourage cost conversations with patients who are interested or in need.

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### CURRENT NEEDS

Indeed, the lack of data on the impact of cost discussions between oncologists and patients presents a tremendous opportunity for descriptive and intervention research. First, we need more research on who discusses costs and who wants to discuss costs. Not all patients desire a cost discussion, but we are limited in our ability to identify those patients. Screening tools for financial distress have been developed and tested [26], and now they need to be disseminated on a large scale with follow-up evaluation of outcomes.

Second, more evidence is needed regarding how cost discussions impact care, costs, and value. As with most treatment-related symptoms, providers may not intervene

unless they are aware of the symptom's impact on a patient's life. The same can be said of financial burden as a side effect of treatment [27]. As such, studies should be designed to prospectively identify and describe patient-provider cost discussions. Critically, those studies need long-term follow-up to determine the impact of those discussions on costs and treatment patterns.

Third, it is becoming increasingly clear that physicians have both an obligation to be good stewards of limited resources and to understand the financial effects of the treatments they prescribe for their patients. Hence, medical students and trainees should be taught early in their careers about how to best engage patients in value discussions. Some of this work has already started, with identification of competencies for health-care value education; those competencies include principles of health policy and insurance, real-world application of value concepts to clinical situations, and systems-level design [28].

Fourth, providers and patients may benefit from more price transparency. A considerable barrier to effective cost conversations is that, in most situations, providers do not know how much a patient will be charged for a service, nor do they know the patient's out-of-pocket liability at that point in time. Insurance companies have begun to add price transparency features to their websites and apps for members, and a number of health information technology companies have begun to make aggregate price data available to the public at large. Preliminarily, the evidence suggests transparency in pricing might help drive down prices and increase competition [29, 30]. However, the availability of real-time, patient-specific data on out-of-pocket costs, as determined by a given patient's coverage plan and status, is limited and, in most cases, is not easily accessible to the provider. Ultimately, payers and health systems should commit to make prices and costs more widely available.

### HOW CAN ONCOLOGISTS IMPROVE VALUE FOR PATIENTS TODAY?

Efforts are under way to address these and other barriers in the form of increased provider training as well as price transparency tools and policy change. However, physicians today do not have the resources they need to address this important patient-care issue. To help address this issue, organizations within the cancer community have begun to devise ways to help. The American Society of Clinical Oncology recently developed the Value Framework, a conceptual framework to help physicians and patients weigh the potential benefits of treatment with possible side effects and costs [31]. The National Comprehensive Cancer Network has established evidence blocks to help inform clinical decision making with a focus on efficacy, safety, quality of supporting evidence, and affordability [32]. Yet, neither of these tools has been broadly tested with physicians and patients in discussions of clinical

benefit, harm, and costs. Adding an additional component to the patient visit may be time consuming for already-busy oncologists. But if adding this step ultimately leads to reduced costs and better outcomes for patients, oncologists may be more than willing to take part, particularly if reimbursement mechanisms are available to compensate oncologists for the additional time devoted to these detailed discussions.

Potential policy solutions that might improve value are on the horizon; these include, for example, chemotherapy parity laws, health-care price transparency laws, value-based insurance design, and new reimbursement models. Yet, these are long-term solutions that are unlikely to help patients receiving treatment today. Based on the existing evidence, how can oncologists improve the value of cancer care now? First, even before considering costs, oncologists could do more to ensure patients understand the goals of care. A large proportion of cancer patients misunderstand the goals of their treatment (up to 81% in one study) [33]. As a result, those patients are at risk for accepting treatment options that might not be in their best interest. For example, detailed and explicit goals of care discussions might prevent some patients from receiving chemotherapy within 3–4 months of dying [34]. Second, oncologists should be aware of the prevalence of financial burden among cancer patients. If, as evidence suggests, 50% of patients with Medicare experience undue financial burden [35], patients experiencing financial burden are going undetected for a variety of reasons, ranging from uncertainty of where to find help to fear of receiving lesser quality of care. By helping patients feel comfortable with the concept of affordability discussions in clinic—distinct from discussions related to overall health expenditure and rationing—oncologists might identify patients at risk for financial burden. Third, oncologists should focus on eliminating use of low-value tests and interventions such as those identified by the Choosing Wisely Campaign of the American Board of Internal Medicine Foundation. These include interventions without proven clinical benefit; interventions with an equally safe and effective, but lower, cost alternative; and interventions that patients might decline if they had a better understanding of goals of care [36]. Keeping in mind these steps, physicians can improve value by discussing costs and clinical benefits with patients.

### AUTHOR CONTRIBUTIONS

**Conception/Design:** Dana S. Wollins, S. Yousuf Zafar

**Manuscript writing:** Dana S. Wollins, S. Yousuf Zafar

**Final approval of manuscript:** Dana S. Wollins, S. Yousuf Zafar

### DISCLOSURES

**S. Yousuf Zafar:** Genentech (C/A), Novartis (E [spouse], OI [spouse]). The other author indicated no financial relationships.

(C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board

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