



Addressing Patients' Priorities as a Strategy to Improve Value

YU-NING WONG,^a NANCY ROACH,^b NEAL J. MEROPOL^c

^aFox Chase Cancer Center, Temple University Health System, Philadelphia, Pennsylvania, USA; ^bFight Colorectal Cancer, Alexandria, Virginia, USA; ^cUniversity Hospitals Cleveland Medical Center Seidman Cancer Center, Case Comprehensive Cancer Center, Case Western Reserve University, Cleveland, Ohio, USA

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The concept of value in medical care is gaining increased attention by policymakers, providers, patients, payers, and the press. However, characterizing, measuring, and optimizing value is a challenging exercise. Although value can be simply defined as treatment outcomes in relation to costs [1], there is a lack of consensus regarding which potential variables should be included in this calculus and how they should be weighted. Clearly, this assessment is dependent on the perspective taken; a societal or payer approach to value assessment may be very different than the considerations of patients with cancer.

Several professional organizations, such as the American Society of Clinical Oncology (ASCO) [2, 3], the National Comprehensive Cancer Network [4], the Institute for Clinical and Economic Review [5], and Memorial Sloan Kettering Cancer Center [6] have proposed frameworks for assessing the value of cancer treatments [7]. Some responses to these efforts have highlighted concerns that the patient "voice" may not have been adequately represented in framework development. For example, FasterCures, a nonprofit center of the Milken Institute, convened a workshop that committed to development of a "value framework that includes a more robust and representative patient perspective and addresses patient value considerations." [8] In an effort to inform our own perspectives on the patient point of view, we reached out to the Patient Advocates in Research listserv (PAIR), which contains approximately 250 members. Listserv members were asked to comment about variables that influence the value of cancer care from the patient perspective. The goal of this outreach was to qualitatively broaden our understanding of the myriad influences on value as seen by patients, to supplement our own perspectives gained through everyday clinical encounters, empirical research, and other interactions with the advocacy community.

We found that patients agree with the inclusion of costs and clinical outcomes in any assessment of value, but that an individual perspective, rather than a societal point of view, is critical. For example, feedback from PAIR indicated that important costs were not restricted solely to the cost of medication, but included other out-of-pocket direct and indirect medical expenses. Such elements include total out-of-pocket expense for medical care, time burden on patient and

caregivers, and travel burden for patient and caregivers. The recognition that costs vary dramatically based on the nuances of insurance coverage, the proliferation of high-deductible insurance plans, and increases in cost-sharing supports the notion that approaches to integrating assessment of value in treatment decision-making must account for individual patient perspectives.

The assessment of clinical outcomes is straightforward in terms of defining key parameters of interest (e.g., curative potential, overall survival, and freedom from relapse). However, communication around clinical outcomes is challenging, given the complex interplay between uncertainty, risk communication, numeracy, hope, and concerns regarding patient understanding of the likelihood of various treatment outcomes [9, 10]. These conversations may differ based on the clinical settings (e.g., palliative versus curative). The quality of this patient-provider communication, and the relationship that establishes a basis of trust, is a key driver of patient value assessments.

Perhaps the greatest influences on patient assessments of value are individual preferences and goals. Value-assessment frameworks that seek to serve as decision aids (rather than solely to be used for decisions about resource allocation by societies or payers) must seamlessly account for these characteristics at the individual level. For example, we found variability in cancer patient preferences for quality and length of life that are associated with patient characteristics and other aspects of treatment decision-making [9]. These preferences may also concern attitudes about side effects, out-of-pocket expenses, family burden, cure versus palliation, or likelihood of reaching a milestone family event. The primary message we obtained from patients was very clear: each patient has a different perspective on what is important to him or her, so the value assessment must be individualized. This places a critical burden on health care teams to adequately assess and address these important domains for individual patients.

These comments highlight the challenges in addressing patients' priorities in assessing the value of cancer care. Although many outcomes (e.g., survival and toxicity) are observable and measurable, they still require patients to make trade-offs among these treatment attributes. High-quality

Correspondence: Neal J. Meropol, M.D., Division of Hematology and Oncology, University Hospitals Cleveland Medical Center, 11100 Euclid Avenue, Wearn 145, Cleveland, Ohio, 44106-5065, USA. Telephone: 216-844-5220; E-Mail: neal.meropol@case.edu Received May 2, 2016; accepted for publication September 2, 2016; published Online First on October 14, 2016. ©AlphaMed Press 1083-7159/2016/\$20.00/0 <http://dx.doi.org/10.1634/theoncologist.2016-0184>

provider-patient communication can improve value by helping patients identify their goals of treatment and potential concerns about toxicity. Patients may have different preferences for efficacy, toxicity, and cost based on their own personal characteristics (i.e., age, cultural values, or personality type) and the treatment setting (adjuvant or palliative) [11]. Conversations that clarify these preferences and trade-offs can be complex and time-consuming; however, they can ultimately increase patient satisfaction and potentially lower cost. Providers could benefit from specific training and must be given the time and resources to more fully explore these issues with patients. For example, some patients with aggressive, incurable cancer may choose aggressive treatment that offers a greater chance for longer survival in spite of increased toxicity and consider this "high value." In contrast, other patients with different preferences may not consider aggressive treatment in this setting high value and may select less toxic therapy and/or hospice. Furthermore, personal financial resources are likely to bear on each patient's willingness to pay for a specific clinical benefit [11]. It is incumbent upon providers to elicit these preferences to optimize value for individual patients. In societies without government-supported universal health care, such as the U.S., financial circumstances can impact access as well as preferences, and hence threaten to increase health disparities [12]. Oncologists have the opportunity and responsibility to be strong advocates for their patients in both the clinical and policy settings.

Patients' preferences for treatment may also be associated with their preferences for their oncologist's communication style. In our own work, we found that patients who indicated a preference for length over quality of life desired an oncologist who spoke more positively, used more general terms, spoke in a more emotionally supportive way, and was less likely to give the worst possible results of treatment [9]. The conversations about the value of treatment are likely highly nuanced and complex. Along with the primary oncology team, palliative care teams may be helpful in guiding the discussion and establishing patients' goals of care [13, 14]. Payers and health care providers should work together to make these services available to all patients with advanced cancer.

Unfortunately, the value discussion is complicated by a lack of transparency in cost information for patients. Unlike certain publicly available cost calculators, such as those provided by insurers and other groups that focus on discrete events such as colonoscopy or elective surgery, oncology care is fluid and occurs over an extended period of time. The fragmented nature of our health care system makes obtaining treatment-related costs at the point of care difficult to obtain for oncology patients [15]. Researchers from the Group Health Research Institute have proposed a treatment cost calculator that compares chemotherapy, pharmacy, laboratory, hospital, and other medical costs along with possible out-of-pocket costs [16]. However, even with this detailed information, this tool includes the following important caveats: "Your health insurance may or may not pay a portion of the costs for the services listed above," and encourages patients to ask, "What is my deductible? Has it been met? What is the portion of the costs I will have to pay? What is the limit on costs I pay out of pocket?"—thus recognizing the uncertainty that patients still face, even when being provided comprehensive information

regarding costs. The Institute of Medicine (IOM) has acknowledged the importance of this information to patients in its definition of "health literate" organizations as those that assist patients in navigating, understanding, and using health care services. One of the attributes of such an organization is that it "communicates clearly what health plans cover and what individuals will have to pay for services" [17]. Based on IOM recommendations, the Oncology Care Model requires that practices provide this information to patients as part of their care-management plans [18].

Providers need greater training in assessing cost as a treatment-related toxicity and understanding how it may affect quality of life. However, managing financial toxicity is a challenging aspiration. How the cost of treatment impacts the value of a treatment may vary greatly based on a patient's other financial resources and responsibilities. Financial distress is a subjective term, and it has been described as a reaction, such as mental or physical discomfort, to stress about one's state of general financial well-being [19]. Patients with financial distress live paycheck-to-paycheck, rather than within the traditional definition of poverty. Therefore, subjective questions about financial distress, such as those measured through the InCharge Financial Distress and Wellness Scale, may be more relevant than hard endpoints such as income or employment status [20]. Because financial catastrophes such as medical bankruptcies are more likely to occur in patients who are traditionally considered middle class through measures such as education and homeownership status [21], it is clear that better measures of financial toxicity from cancer treatment should be implemented.

One potential tool that may help characterize whether patients are developing financial toxicity for cancer treatments is the COST measure [22]. This patient-reported outcome measure is designed to characterize the financial distress experienced by cancer patients. However, even when financial distress is identified, managing this is complex. Unlike "typical" toxicity measures such as nausea or fatigue, many physicians state that they are untrained in addressing these concerns. Furthermore, even among providers with the relevant interest and skills, it is challenging to address financial concerns. A survey of 333 ASCO members found that 40% addressed costs rarely, or never, and that the greatest barrier to these discussions was a lack of resources [23]. This finding is consistent with studies of other providers. For example, a focus group of social workers and counselors identified the complexity of care and limited resources as barriers to effectively helping patients address financial concerns [24].

Additional resources and training could aid providers in discussing the value of treatment with their patients. This is particularly important because concerns about treatment-related cost may impact a patient's ability to make high-quality treatment decisions, such as whether to enroll in a clinical trial [25]. Providers need to be able to guide patients regarding the risks and benefits (including financial toxicity) of alternative treatment options to help them choose treatments that reflect their preferences and values. To improve the content of the discussions, providers need more transparent information and resources to effectively counsel their patients about their risk of financial toxicity associated with treatment. ASCO's recently updated value framework provides information regarding

Panel 1: Elements that affect value for patients

Treatment characteristics

Clinical setting and goals (adjuvant vs. advanced disease, curative vs. palliative)
 Magnitude and type of clinical benefit
 Cost to patient
 Toxicity (long- and short-term)
 Delivery (e.g., oral vs. i.v., frequency of treatments, time without treatment)

Patient characteristics

Preferences and goals
 Health status (ability to tolerate and benefit from treatment)
 Understanding of risks and benefits
 Ability and willingness to pay for treatments

Provider characteristics (physician, health care system)

Ability to explain treatment characteristics to patient
 Ability to provide transparent cost information and access to financial counselors
 Ability to provide access to palliative care and social work services
 Ability to provide access to care to rapidly manage toxicity

Panel 2: Tools and resources needed to assist patients and providers in assessing value of cancer treatment

1. Provider education in communication about value of cancer treatment from patient perspective
2. Tools to help define individual patient preferences, goals, and values
3. Point-of-care resources for defining expected clinical outcomes, toxicities, and out-of-pocket costs of treatment options
4. Decision support to help weigh the relative importance of clinical outcomes, toxicities, and costs of treatment options
5. Availability of providers, financial counselors, and other support services to assist patients in making preference-sensitive treatment decisions based on the value of therapeutic options to individual patients

clinical benefit, toxicity, net health benefit (reflecting both benefit and toxicity), and costs; to facilitate clinical utility, a future plan includes development of a point-of-care tool that permits weighting of outcomes based on individual preferences [2, 3].

In summary, the individual patient perspective is critical to inform assessments of value that drive treatment decisions in the clinic. Although addressing patient preferences to increase the value of cancer care seems straightforward, there are many elements that patients and providers must weigh in assessing therapeutic options (Panel 1). It is important to note that many members of the health care team impact patients' assessments of value, including advanced practice clinicians, nurses, social workers, and financial counselors. Each of these providers, and their patients, need guidance, training, and time to elicit, clarify, and review preferences for the efficacy, toxicity, and cost of alternative treatment options. Novel decision support tools should be designed to help patients clarify their preferences and goals for

treatment and, ultimately, assess the value of therapeutic options (Panel 2). The quality of communication between patients and their providers about the value of treatment should be recognized as an essential driver of high-quality cancer care.

AUTHOR CONTRIBUTIONS

Conception/Design: Yu-Ning Wong, Nancy Roach, Neal J. Meropol
Provision of study material or patients: Yu-Ning Wong, Nancy Roach, Neal J. Meropol
Collection and/or assembly of data: Yu-Ning Wong, Nancy Roach, Neal J. Meropol
Data analysis and interpretation: Yu-Ning Wong, Nancy Roach, Neal J. Meropol
Manuscript writing: Yu-Ning Wong, Nancy Roach, Neal J. Meropol
Final approval of manuscript: Yu-Ning Wong, Nancy Roach, Neal J. Meropol

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For Further Reading:

Dana S. Wollins, S. Yousuf Zafar. A Touchy Subject: Can Physicians Improve Value by Discussing Costs and Clinical Benefits With Patients? *The Oncologist* 2016;21:1157–1160.

Excerpt:

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. 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.