Value of High-Cost Cancer Care: A Behavioral Science Perspective

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ABSTRACT

Concerns about the high costs of cancer care have led to a renewed interest in understanding how patients value the outcomes of care. Psychologists, economists, and others have highlighted some of the ways in which patients and caregivers perceive and make treatment decisions. Prospect theory is the predominant framework for understanding decisions made in situations where the outcomes of each choice are uncertain. Prospect theory assumes that a patient values the outcomes of care not in absolute terms, such as years of life saved, but as deviations from the patient’s point of reference. This article discusses some of the implications of this notion, along with discussing differences among people in their reference points. These and other considerations from the psychology of decision making help to clarify why some patients might be inclined to seek expensive or risky treatments in the hopes of achieving benefits that others might consider not worthwhile. An appreciation of these psychological issues might improve the quality of debates concerning the rising costs of cancer care.

INTRODUCTION

Debate about the rising costs of cancer care has made clear that some people would pay more money and/or take greater risks in the hopes of receiving benefit from cancer care. Behavioral scientists examine this phenomenon in terms of how people value the outcomes of cancer care. There are many questions here. How does the perceived value of care differ depending on who is asked? Does our framework for evaluating care change when assessing life-saving therapy, supportive care, alternative therapies, or palliative care? In recent years, researchers in the fields of behavioral economics, medical decision making, and social psychology have done much to improve our understanding of these issues. An appreciation of these psychological issues might improve the quality of debates concerning the rising costs of cancer care. In what follows, I describe the prevailing psychological account of how people value treatment options and how this can clarify differences between people and within a person over time in the demand for higher-cost care.

Patients value the outcomes resulting from care relative to a reference point

According to the predominant theory of decision making under conditions of risk, prospect theory, people do not make decisions based on the absolute amount of the outcome, but rather on what that amount means to them. In the domain of money, this is well understood by most people. A gamble that might increase someone’s wealth by $500 will be valued differently by one’s wealth by $500 will be valued differently by
people with different household incomes. Hence, some people might be more willing to take a risk to win the $500. Similarly, not everyone will perceive the same value for a treatment that will increase survival by 5 years. Some people would take more risk or pay more money for that increase in survival than would others. It all depends on one’s point of reference. In their groundbreaking work on prospect theory, psychologists Daniel Kahneman and Amos Tversky posited that people value outcomes relative to a reference point. According to prospect theory, the absolute value of the outcome is not what determines people’s health care decisions. Rather, the values that drive care decisions are based on the direction—gain or loss—and magnitude of the change in health relative to the reference point. How exactly the reference point is determined and how it might change is a topic of much current research. More will be said on this when discussing differences within and among people in their reference points.

Consider a 60-year-old man who expects to live until at least the age 85 years. His reference point in terms of survival is thus 25 years. Imagine that the man then receives a diagnosis of pancreatic cancer and is told that cases such as this usually lead to death in about 1 year. Relative to this reference point, 1-year survival is valued as a massive loss (eg, $25 − 1). Consider another man with severe heart disease that has, at the age of 60, necessitated a heart transplant. The prognosis is not especially good, such that the man is expected to live another 5 years at most. Having dealt with the trials and tribulations of his heart condition for much of his life, this man knew his life expectancy without transplantation was shortened a great deal. He accepts this latest prognosis, and so 5-year survival becomes his reference point. Were this man then to be diagnosed with pancreatic cancer that gave him an estimated 1 year to live, the loss would be valued relative to the reference point of 5 years (eg, $5 − 1). These two examples demonstrate how a given outcome of 1-year survival may be valued differently depending on the person’s reference point.

One recent attempt to measure the magnitude of loss experienced was reported by Gaskin et al. The authors examined the decision of some patients to participate in phase I oncology trials at a time when many regarded these trials as risky endeavors with little chance of benefit. (There is evidence that more recent phase I trials do not have such unfavorable risk-benefit ratios.) Some patients who are offered phase I trials are newly diagnosed patients with aggressive disease. Such patients might still be operating from a reference point that is closer to their prediagnosis life expectancy. For these patients, being given 2 years to live is experienced as a significant loss. Other patients who are offered participation in phase I trials may have had some form of cancer for the last 5 to 7 years and have tried many treatments. These patients might have adjusted their reference points to something closer to their postdiagnosis life expectancy. Gaskin et al asked 207 patients to indicate how much of their “life’s fullness” they had lost as a result of their cancer. The question was phrased intentionally to allow patients to report on the loss of quantity and/or quality of life. There was great variability among the responses to this question. More important, those patients who reported losing more of life’s fullness were more likely to agree to participate in a phase I clinical trial.

According to prospect theory, the value of a gain or loss in life years is not based on a simple one-to-one relationship between years of survival and value. There is a curvilinear relationship between value and health, whether health is measured in terms of survival, functioning, quality of life, and so on. Figure 1 shows the relationship between survival time and the value of survival time for a hypothetical person. Such a relationship is known in prospect theory as the value function. In this case, the person’s reference point is 5 years. Such a person might have a lower reference point because he has adapted to his postdiagnosis health by adjusting his reference point to be more consistent with his postdiagnosis prognosis. Any outcome greater than 5 years is seen as a gain, and any outcome less than 5 years is seen as a loss. The value of a treatment that would provide 5 years of survival would be zero, since this is equivalent to this person’s reference point. For both gains and losses, the relationship between value and years of survival is curvilinear. That is, initial gains in life expectancy from 5 to 10 years are valued very highly, but the value of additional gains in life expectancy beyond 10 are of lesser value to the person. Similarly, initial losses from between 5 and 2 years of life would be experienced as large changes in value. Additional losses beyond, say, 2 years of life would add less to the overall sense of loss.

This has important implications for understanding people’s care decisions. Imagine a patient who is considering two different chemotherapy regimens, A and B. Regimen A is expected to have a slightly better outcome than regimen B, resulting in an incremental benefit of 1 additional year of survival, but is more expensive than regimen B. How much more money would a patient pay for the additional 1 year of survival? From the standpoint of prospect theory, this will depend on where the incremental treatment benefit occurs relative to the patient’s reference point. Looking at Figure 1, it is clear that the difference between regimens would be seen as more important to the patient if the difference was between 7- and 8-year survival versus 14- and 15-year survival. Both differences equal 1 year of life, but they
translates into different values for the patient’s decision making because of the curvilinear relationship between value and benefit. Thus, a patient might be expected to tolerate greater expense or risk for regimen A over regimen B when the difference is felt close to the patient’s reference point. This helps to explain why some patients appear to go to great lengths to receive a treatment whose absolute level of benefit does not warrant such efforts from an outsider’s perspective.

**PEOPLE CARE MORE ABOUT LOSSES THAN GAINS**

Another implication of prospect theory is that a 2-year change in life expectancy is valued differently depending on whether those 2 years are viewed as a gain or a loss. This can be seen clearly in Figure 2, where the decline in value for losses is steeper than the rise in value for gains. This so-called loss aversion means that losses loom larger than gains. Small incremental improvements in years lost near the reference point are valued much greater than equivalently small incremental improvements in years gained near the reference point. Adding to what was discussed in the previous section, one can expect that differences between treatments are magnified if (1) differences in outcomes occur close to that person’s reference point, and (2) the person perceives the outcomes as reductions in losses. Because there is greater value at stake, people might be willing to take greater risks (eg, accepting greater risks of adverse effects or greater uncertainty about treatment benefits) and/or pay more money for the additional benefit.

The tendency to assign greater value to losses than to gains also explains how people can view a treatment differently when outcomes are framed as losses rather than gains. In their classic study on preferences for treatment, McNeil et alasked outpatients, radiologists, and business school students to select either surgery or radiation therapy to treat a hypothetical case of lung cancer. Surgery was assumed to have a 10% chance of perioperative death. Some participants were presented with outcome data framed in terms of the chances of survival, whereas others were presented with mathematically identical data that were framed in terms of mortality. The authors expected that people would care more about the 10% additional risk of mortality associated with surgery if this additional risk was presented as a greater loss (mortality) than as a lesser gain (survival). This is because, as shown in Figure 2, the slope of the value function for losses is steeper than that of gains, amplifying small differences in loss between treatments near the reference point. Consistent with expectations, the authors found that all three groups—patients, physicians, and students—selected radiation over surgery with greater frequency when the outcomes of each were presented in terms of mortality (42% v 25%). This underscores the importance of considering whether patients compare treatment benefits in terms of differences in losses or gains.

**NOT EVERYONE’S REFERENCE POINT IS THE SAME**

The preceding discussion has underscored the critical role of the reference point in explaining the health care choices patients make. Patients could evaluate potential health outcomes using the reference points of their past health state, current health state, or some future health state to which they aspire. It is reasonable to suspect that, for many people, a combination of perspectives contribute to their reference point. For example, Gaskin et alasked a patient might evaluate outcomes of care in terms of the patient’s relative health stock. Relative health stock is based on the difference between a patient’s quality-adjusted life expectancy before receiving the diagnosis of cancer and after the diagnosis.

One of the most interesting areas of current research in medical decision making concerns the study of how people adapt to their changing health states, including how their reference point changes. As was discussed earlier, a newly diagnosed patient might perceive different treatment options in terms of his prediagnosis reference point, whereas someone who has had a longer history of cancer with periods of improvement and decline might be better able to adjust her reference point on the basis of new prognostic information. It is important to remember that people make judgments based on reference points for a broad range of outcomes. How changes in the reference point occur likely depends on the type of outcome. For example, the reference point for life expectancy might change as a function of receiving more information. Changes in the reference point for quality of life might occur as the person reconsiders what constitutes “normal daily activities,” what it means to live a satisfying life, or what it means to really suffer. Daniel Kahneman, one of the developers of prospect theory, has recently stated that the study of how people adapt to changing health is a top priority.

When people who do not have cancer are asked to consider the costs of cancer care, they must invariably put themselves in the shoes of someone suffering from cancer to determine the value of the benefit obtained from some (costly) treatment. Behavioral scientists refer to this as “affective forecasting”—predicting how one would feel in a situation that has not yet been realized. Research on the accuracy of
people’s affective forecasts—whether for health states or the pleasure associated with candy bars—has demonstrated that people are often very poor at predicting how they will feel in the future. Typically, people overestimate how bad a bad state would be and how good a good state would be. For example, Boyd et al.11 examined ratings of quality of life for patients with rectal cancer who had received a colostomy. The authors found that people other than the patients tended to view the patients’ quality of life worse than the patients did. These other people included care providers, healthy adults, and people with rectal cancer who were treated with radiotherapy rather than colostomy. At least in this case, people were not particularly good at putting themselves in the patient’s shoes.

Social scientists are examining a variety of reasons that people are sometimes so bad at evaluating how bad or good a future state of health will be.12 As discussed earlier, people might not appreciate how much patients can change their point of reference when valuing a health state. Another possibility is that, in imagining what it would be like to, say, live with a colostomy bag, people tend to focus only on that aspect of the person’s life that would be different (ie, having a colostomy bag) and to ignore all other aspects of the person’s life that might determine the person’s well-being. (For a readable and up-to-date review of these issues, see Ubel.13) Efforts to determine which mechanism is responsible for problems in predicting patients’ states of health are ongoing.14

This work on changing reference points and differences among people in their reference points brings up a difficult question. In making decisions about cancer care and how much should be spent, whose values should be used? Newly diagnosed patients? Patients who have already experienced some benefit from treatment? Health care providers? Members of the general public, including many who have never had cancer? Behavioral science has been helpful in describing how and why the values of these various players differ. It remains for policy makers, bioethicists, and others to answer this normative question.15

Some might wonder why patients would go to great lengths for a benefit of such small magnitude. The discussion up to this point has attempted to show how prospect theory accounts for the value placed on the outcome of care relative to the patient’s reference point. But a person might also wonder why, apart from the magnitude or value of the benefit, a patient would go to great lengths for a benefit that had a relatively low probability of occurring. According to prospect theory, people do not use chances of success or failure directly in their decision making. Rather, people transform the probability information they hear into some other form, called decision weights. In terms of decision weights, people tend to look at the benefit (or harm) as happening, possibly happening, or not happening.

Work by our group16-19 has focused on a related issue regarding how patients understand the chance of benefit. Most of the time, clinicians refer to population statistics when discussing the likelihood that a patient will experience benefit (or harm) from a specific treatment. For example, “For patients with your condition, we usually see approximately 30% respond favorably to this type of chemotherapy.” This is known in the philosophy of probability as a frequency-type probability, because it refers to the relative frequency of events over the long run.17,20 As Claude Bernard wrote in 1865, however, “You can tell your patient that, of every hundred such cases, eighty are cured . . . but that will scarcely move him. What he wants to know is whether he is numbered among those who are cured.”21 In other words, the patient is likely to be making this treatment decision one time, and so the patient might be less concerned about the long-run probability and more concerned about how likely she will be to have a positive response this time. This is sometimes known as the belief-type probability. Thus, a patient could say that she understands that fewer than 10 out of every 100 patients will respond to treatment, while at the same time believing that she is 95% confident that she will be one of the ones to benefit. For example, in our study12 of patients considering participation in phase I trials, we asked patients to imagine a study in which 20 of 100 patients were expected to benefit. Patients then indicated how confident they were that they would be among those to benefit. If patients equated the population probability with their belief-type probability, we would expect most people to say they had a 20% chance. In this case, however, 44% of the patients reported that they would definitely be one of the ones to benefit. Is such optimism unrealistic and ultimately detrimental, benign, or actually beneficial? Much work in the psychology of risk perception, medical decision making, and bioethics is directed toward answering this question, but there is little consensus.17,22,23

In cases where the benefit of care is not in terms of preserving years of life, behavioral scientists have discovered other interesting findings about how people characterize benefit. For supportive or palliative care, the options for care are evaluated in terms of how they might make a patient feel. Valuing this type of benefit is also subject to the patient’s reference point, as was discussed earlier. In addition, however, behavioral scientists have shown that people’s health care choices can depend on the way in which people recall and summarize their experiences. This was dramatically illustrated in a study conducted by Redelmeier et al.,24 who randomly assigned patients undergoing colonoscopies to one of two groups. One group underwent a standard colonoscopy. For the other group, the colonoscopy was allowed to remain in the rectum for up to 3 minutes before being removed, with no suction, inflation of bowels, or added anesthetic. Patients in this group perceived the colonoscopy to be less aversive, even though they experienced more total pain than patients who underwent the briefer, standard colonoscopy. Furthermore, those who experienced the added time of lower-intensity pain were more likely to return for a repeated colonoscopy. Thus, in valuing their experience of pain over time, these patients appeared to have given stronger weight to the most recently experienced pain (the 3 minutes of lower-intensity pain). Effects such as these make it difficult to characterize the quality of any particular health state that patients have experienced.

In a recent survey of 138 academic oncologists, 71% agreed that growing costs over the next 5 years would require greater rationing.25 In this environment, there will be an even greater need to understand
how the benefits of new cancer treatments are viewed. In this article, I described prospect theory and other related developments in the behavioral sciences that can help us to understand the decisions and the challenges that cancer patients and their caregivers face. This work helps to explain why some patients will demand expensive care that might not appear to generate sizeable benefits from the perspective of others. The increasing challenge of managing health care resources within cancer care must be undertaken with an appreciation of the evolving field of the psychology of decision making.

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REFERENCES


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