Linking Decision-Making Research and Cancer Prevention and Control: Important Themes

Kevin D. McCaul  Ellen Peters
North Dakota State University  Decision Research

Wendy Nelson and Michael Stefanek
National Cancer Institute

This article describes 6 themes underlying the multiple presentations from the Basic and Applied Decision Making in Cancer Control meeting, held February 19–20, 2004. The following themes have important implications for research and practice linking basic decision-making research to cancer prevention and control: (a) Traditional decision-making theories fail to capture real-world decision making, (b) decision makers are often unable to predict future preferences, (c) preferences are often constructed on the spot and thus are influenced by situational cues, (d) decision makers often rely on feelings rather than beliefs when making a decision, (e) the perspective of the decision maker is critical in determining preferences, and (f) informed decision making may—or may not—yield the best decisions.

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The Basic and Applied Decision Making in Cancer Control meeting brought together basic judgment and decision-making researchers and applied behavioral scientists representing different disciplines and perspectives on the science of decision making. Despite this diversity, several common themes ran through the various presentations and discussions. The purpose of this article is to describe these themes and highlight their potential importance for future research in decision making related to cancer prevention and control. The themes are as follows: (a) Traditional decision-making theories fail to capture real-world decision making, (b) decision makers are often unable to predict future preferences, (c) preferences are often constructed on the spot and thus are influenced by situational cues, (d) decision makers often rely on feelings rather than beliefs when making a decision, (e) the perspective of the decision maker is critical in determining preferences, and (f) informed decision making may—or may not—yield the best decisions.

Traditional Decision-Making Theories Fail to Capture Real-Life Decision Processes

Classical theories of decision making presuppose that people have well articulated values and preferences that guide their decisions. Such models rely on *utilities*, a valuation of all the possible outcomes of a decision. The utility of each outcome is combined with the probability associated with that outcome to yield a numeric score. So, for example, a woman newly diagnosed with breast cancer might have to evaluate the nature and probabilities of the various outcomes associated with lumpectomy versus mastectomy and consider the values for each of her options. A consideration of utilities should help a decision maker select the “best” option. Such models provide the normative answer to decision problems.

One assumption of utility models is that people will make better decisions if they just think longer and harder. However, researchers have known for some time that people often do not operate in the way that classic decision models envision. Simon (1955) noted that people are rational but only in a limited way ("bounded rationality"). Rather than consider all possible options, people “satisfice” by using mental shortcuts or heuristics to make choices that are good enough but not necessarily optimal. Damasio (1994) argued that decision makers often rely on feelings in addition to or instead of rational beliefs, a theme to which we return below. Others have found that too much introspection can lead to suboptimal decisions (Wilson et al., 1993; see also Hammond, Hamm, Grassia, & Pearson, 1987).

Thus, normative decision theory may fail to account for or improve many of the decisions relevant to cancer control. People confronting cancer are often in a state of information overload, bombarded with information, options, and choices. Moreover, the information is often incomplete or difficult to interpret. In this
issue, Fischhoff (2005) provides examples of the decision complexities surrounding what might be considered relatively simple choices (e.g., tanning). He also suggests that decision-making researchers should consider doing a normative analysis as they embark on a research program. A careful analysis of the options, outcomes, relevant values, and uncertainties associated with a decision may provide an important benchmark (i.e., the fully informed decision maker) against which to compare how people actually make decisions in that context and may highlight ways in which decisions can be improved.

Decision Makers May Be Unable to Predict Future Preferences

It is important to recognize that normative decision models were not intended to describe how decision making actually occurs but rather to describe how decisions ought to be made. To make good decisions, however, requires decision makers to project how they will feel about various future outcomes—it implies that people have established preferences. But how can a woman decide what breast cancer treatment is best for her if she has never experienced a lumpectomy and does not know how she will feel after undergoing that procedure? Many, if not most, cancer-related decisions are predicated on expectations of unfamiliar or uncertain health states. For example, a man who must choose between different treatments for prostate cancer might select watchful waiting as opposed to surgery because of a belief that he would be devastated by possible side effects of the surgical treatment.

In a surprising number of situations, research demonstrates that people are poor predictors of their future feelings (Wilson & Gilbert, 2003). In this issue, Connolly and Reb (2005) review evidence that decision makers mispredict how much regret they will experience and that their decisions depend on these mispredictions. The direction of mistakes is also biased; in particular, people underestimate their likely happiness when confronted with negative life conditions (Albrecht & Devlieger, 1999).

The implications of people’s inability to predict future preferences are critical for decision making related to cancer. As Peter Ubel and colleagues (Ubel, Loewenstein, Schwarz, & Smith, 2005) point out, a woman with a BRCA mutation might make a suboptimal treatment decision that is based on an inaccurate prediction about how she would feel after different surgery procedures. Likewise, people might be more likely to request life-sustaining treatment after living with cancer, whereas others might reject such treatments prior to going through the cancer experience (see Ditto & Hawkins, 2005).

How might researchers and practitioners help people do a better job of predicting the future? Some researchers have tried to direct the attention of persons imaging the future. For example, one might ask someone contemplating an operation for cancer to think about all of the activities he or she engages in that will be unaffected by possible side effects. It is unclear how useful such attentional focusing will be (Ubel et al., 2005).

Preferences Are Constructed

Normative decision-making theories assume that people have well established preferences and values. However, recent research suggests that preferences are often constructed in the process of being elicited. Consequently, preferences may be labile and subject to the influence of situational cues (Slovic, 1995). Woloshin, Schwartz, Black, and Welch (1999) illustrated this phenomenon, showing that a woman’s expression of her breast cancer risk depended on how the researchers asked the question. When asked in numerical terms (as a number out of 1,000), most women overestimated their risk, but when asked in comparative terms (e.g., “Is your risk higher than, the same as, or lower than that of an average woman of your age?”), they made more accurate risk judgments. It appears that women knew more about their actual risks but constructed their numerical risk estimates from cues in the situation (Slovic, 2000).

In this issue, Johnson, Steffel, and Goldstein (2005) describe how irrelevant situational factors can affect decision making when people do not have preexisting preferences. Also, Ditto and Hawkins (2005) reveal that preferences for different end-of-life treatments are unstable over time. Here—if anywhere—one might expect that people would have consistent beliefs, as they are expressing their preferences about how they wish to die. However, the data suggest that they do not have stable preferences, and thus, today’s best decision may not be tomorrow’s best decision. Given the instability of preferences, Johnson et al. (2005) propose a strategy for producing better decisions: the careful identification of default options. But they caution that using default options may be interpreted as paternalistic in that they imply a single best choice.

Both Affect and Beliefs Are Important

One important way in which the traditional approach to decision making fails to capture real-world decision making is that it fails to consider the role of affect in decision making. The neglect of affect may be especially important when it comes to cancer-related decisions, as the mention of cancer may engender strong emotion.

In this issue, Slovic, Peters, Finucane, and MacGregor (2005) examine the “affect heuristic,” a decision-making strategy that bases decisions on the rapidly experienced good and bad feelings attached to decision alternatives. They propose that reliance on feelings will sometimes improve decision making and other times harm it (see also Blanchette & Richards, 2004; Wilson, Dunn, Kraft, & Lisle, 1989). Other contributors to this issue also highlight the critical role of affect in decision making. Connolly and Reb (2005), for example, emphasize that anticipating regret can lead to the selection of different alternatives. Chapman (2005) and Loewenstein (2005) describe how preferences and decision making are influenced by whether one is in a “hot” or “cold” motivational–emotional state.

Other contributors describe specific cancer-related decisions that demonstrate the relevance of affect to decision making. Revenson and Pranikoff (2005) show how anxiety about breast cancer recurrence may lead women to make decisions that place them at greater health risk. Myers (2005) presents empirical findings demonstrating that men depend partly on affective factors when deciding whether to undergo prostate cancer screening, and both men and women report that affective factors influence their decisions about whether to have genetic testing for colorectal cancer. Schwartz, Peshkin, Tercyak, Taylor, & Valdimarsdottir (2005) identify anxiety as a crucial determinant of decisions related to breast cancer genetic testing and medical management.
Taken together, these data suggest that affect is a critical feature of decision making in cancer.

The Role of the Decision Maker in Determining Preferences

Treatment preferences often vary according to who is the decision maker (patient or physician) and the emotional state of the decision maker at the time of the decision. Elstein, Chapman, and Knight (2005) found that clinicians’ judgments concerning a patient’s best interests may correspond poorly with those of the patient. They propose two possible explanations for this disconnect. First, patients may not be good at predicting what their quality of life will be in another health state. Second, patients and physicians may construct their judgments on the basis of different reference points: Patients may make comparisons to their prediagnosis state, whereas physicians may make comparisons to the long-term outcomes of other patients. Patients’ preferences can also be affected by the disability paradox (Ubel et al., 2005), in which healthy people overestimate the impact of chronic illness and disability. Ubel et al. argue that this misperception largely results from people’s tendency to neglect or underestimate how individuals adapt to chronic or disabling conditions.

Although it is understandable that different people judge and decide in different ways, it is less easy to rationalize why the current—but temporary—emotional state of an individual should also influence judgments and decisions. Articles in the special issue, however, highlight exactly this notion. Loewenstein (2005) discusses this concept in terms of a hot–cold empathy gap. He argues that a person may behave in apparently inconsistent ways depending on whether he or she is in a “hot,” emotionally aroused state or a “cold,” dispassionate state. Empathy gaps occur when a person who is in a hot state cannot understand the reasoning of a person in a cold state. Loewenstein proposes that these so-called empathy gaps can explain, at least in part, why patients’ treatment preferences may shift along with their emotional state. For example, a patient who is experiencing pain may have vastly different treatment preferences when she is receiving adequate analgesia for pain, and men diagnosed with prostate cancer may prefer more intrusive treatment because the fear and anxiety elicited by the diagnosis feel as if they will last forever. Chapman (2005) links the idea of multiple selves (one “self” in a hot state and a different “self” in a cold state) to the concept of time preferences—the values assigned to future outcomes such as getting lung cancer relative to immediate outcomes such as smoking cigarettes.

Informed Decision Makers

In recent years, the preferred physician–patient relationship has shifted from one in which the physician held the decision-making authority (a paternalistic model) to one in which the patient and physician share in the decision-making process (an informed decision-making model or a shared decision-making model). According to Rimer, Briss, Zeller, Chan, & Woolf (2004), informed decision making occurs when an individual comprehends the risks, benefits, and uncertainties of treatment, considers his or her preferences, and makes a decision consistent with those preferences. In this issue, Siminoff and Stept (2005) argue that informed decision making is lacking because of poor communication between patients and professionals. They encourage physicians to ask patients about their preferences for shared decision making, but they also point out that patients must retain the right to identify how and how much they wish to participate in decision making.

Although this approach to decision making may be appealing because it emphasizes the ethical ideals of patient autonomy and respect for persons (The Belmont Report; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), it may not always produce optimal decisions. Many of the contributors to this issue suggest why, under certain circumstances, other approaches to physician–patient decision making may be more appropriate. Fischhoff (2005) reminds us that interventions often operate by using persuasion. Community programs to increase the number of women who obtain a mammography screening, for example, are rarely concerned with creating a shared decision process; they are intended to persuade. Fischhoff does not suggest that such programs are necessarily wrong; instead, he suggests that the default stance should be nonpersuasive, and he discusses the assumptions that underlie a persuasive approach.

A decision-making approach that excludes the individual may also be appropriate when people simply want to avoid involvement. Luce (2005) introduces an “emotional tradeoff difficulty” model, showing how the emotional tradeoffs that characterize a decision can generate threat. In response to threat, some individuals may cope by attempting to minimize “decision-generated negative emotion” or by avoiding deciding altogether. Luce suggests that, in the face of an affectively charged, threatening decision, a paternalistic approach in which the physician voices a strong recommendation may facilitate the patient’s coping efforts.

Along the same lines, Loewenstein (2005) argues that when patients are in a so-called “hot” affective state (such as experiencing pain or anger), they may fail to make decisions that are in their own best interest. Patients who are in a hot state, such as extreme anxiety or depression, may be unable to imagine themselves in a colder, less distressed state. Consequently, they may be ill equipped to make critical health decisions that have long-term consequences, such as end-of-life decisions. Loewenstein points out that in such affectively charged situations, having the physician assume a paternalistic stance may be in the patient’s best interest. A similar argument in support of substituted judgment is made by Elstein et al. (2005), who propose that the clinician may well have a better idea than the patient of what is in that patient’s long-term best interest.

An alternative to the strict paternalistic model is libertarian paternalism (Thaler & Sunstein, 2003), an approach that recognizes that it is virtually impossible to frame information in a truly neutral manner. Within this model, the individual retains freedom of choice for a set of options that have been ordered in such a way that individuals will be steered to select the option that is most likely to promote their welfare. Examples include default options, as described by Johnson et al. (2005). Johnson et al. point out that defaults matter, particularly when individuals are reluctant to make any choice at all.

Implications and Conclusions

Decision making occurs at all points along the cancer continuum, from prevention to palliative care. Researchers attempting to
expand their knowledge of decision making in cancer may benefit by attending to the themes presented above in conceptualizing and designing their research questions. To illustrate, consider the work conducted in the area of genetic testing for breast cancer susceptibility, which has focused extensively on providing risk information to patients (cf. Stefanek, Hartmann, & Nelson, 2001). Genetic testing is valuable because approximately 5%–10% of breast cancer cases demonstrate a pattern of autosomal dominant inheritance. This pattern involves the transmission of cancer predisposition from generation to generation, with approximately 50% of susceptible individuals inheriting the genetic alterations identified as BRCA1 or BRCA2. Breast cancer risk by age 70 among women with such alterations ranges up to 65%, with a parallel, although lower, increased risk for ovarian cancer with BRCA1 (up to 38% by age 70). Uncertainty is plentiful in this context. For example, defined parameters of who should be tested are unclear, and the interventions available for the prevention or early detection of breast cancer for those testing positive are not failsafe. Women can choose a strategy to detect breast cancer early, should it develop (mammography, clinical breast exam, breast self-examination), or a strategy intended to prevent breast cancer surgically (mastectomy or salpingo-oophorectomy). In addition, researchers are testing new screening strategies (e.g., magnetic resonance imaging, digital mammography) and chemoprevention agents for the primary prevention of breast cancer (e.g., raloxifene) for high-risk women.

How could the decision-making themes we have raised in this article apply to decisions about genetic testing? The following questions are sparked by the six themes presented here:

**Traditional Decision-Making Theories Fail to Capture Real-Life Decision Processes**

Do women weigh all alternatives equally to make a rational decision about whether to be screened? We suspect not, given the real likelihood of information overload. What subset of beliefs is most important in guiding women’s decisions? What is the role of affect in such an emotionally charged decision?

**Decision Makers Are Often Unable to Predict Future Preferences**

Can women accurately project their future quality of life with the selection of prophylactic surgery versus screening (or vice versa)? How might their predictions compare to the reports of women who have already adopted one or the other of these treatments? How might they feel if they opt for screening and a cancer is ultimately detected that requires active treatment, or in the case of BRCA1/2 testing, if they select surgery and then breast cancer advances in the future make such surgery obsolete? Are decision makers in this scenario able to predict future regret or the degree to which they can dismiss the chronic worry of developing cancer?

**Preferences Are Constructed**

How might decisions vary according to the content of the clinical situation and the framing of alternatives? How stable are treatment-related decisions? Will women express the same preferences immediately following counseling as they would a week or 2 later?

**Both Affect and Beliefs Are Important**

What feelings does a woman experience as she discusses genetic testing and follow up, including the consequences for her children, her future, and her relationships? Does disclosure about other close family members who have developed and perhaps died from the disease create feelings of sadness, worry, or fear, and if so, how do these emotions affect decision making?

**Preferences Are Constructed on the Basis of “Who I Am” As a Decision Maker**

Do patients and health professionals, in part because of their different roles, begin with different preferences for engaging in genetic testing and selecting one treatment versus another? Do individual differences in values affect the decision to have preventive surgery versus screening?

**Informed Decision Makers**

In genetic testing, might there be individuals who wish to avoid decision making or who want information but prefer to allow the decision to rest in the hands of expert medical professionals? What is the default option if women decide not to decide, and is it the best one?

In future cancer control and decision-making research, it behooves investigators to consider these themes and how they might inform research. Clearly, not all themes will apply to all cancer control questions. However, for too long such issues and others addressed in this special issue have not been aggressively integrated into the questions asked, and our knowledge base has suffered. Consideration of such issues will benefit both health care providers and patients.

**References**


