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# Decision Making and Cancer

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*We review decision making along the cancer continuum in the contemporary context of informed and shared decision making in which patients are encouraged to take a more active role in their health care. We discuss challenges to achieving informed and shared decision making, including cognitive limitations and emotional factors, but argue that understanding the mechanisms of decision making offers hope for improving decision support. Theoretical approaches to decision making that explain cognition, emotion, and their interaction are described, including classical psychophysical approaches, dual-process approaches that focus on conflicts between emotion versus cognition (or reason), and modern integrative approaches such as fuzzy-trace theory. In contrast to the earlier emphasis on rote use of numerical detail, modern approaches emphasize understanding the bottom-line gist of options (which encompasses emotion and other influences on meaning) and retrieving relevant social and moral values to apply to those gist representations. Finally, research on interventions to support better decision making in clinical settings is reviewed, drawing out implications for future research on decision making and cancer.*

**Keywords:** heuristics and biases, decision aids, medical decision making, informed decision making, risk communication

**D**ecision making about cancer—especially about cancer treatments—might seem to be a simple matter: Choose the option that prolongs life most. If treatments are equivalent in prolonging life, then choose the one that maximizes quality of life (e.g., has fewer side effects). However, research has shown that cancer decisions are not so simple. This research illuminates how people make such high-stakes decisions and how to help people make decisions that improve their physical and mental health.

In this article, we provide a brief overview of research on decision making and cancer. Our main goal is to encourage additional research on this important topic by highlighting what is known, identifying crucial gaps in understanding, and laying out the challenges of achieving informed and shared decision making (i.e., decision making in which patients comprehend the relevant facts and share authority with health care providers). Our secondary goal is to relate current research to the major theoretical frameworks that explain and predict decision making to encourage hypothesis-driven research that builds on prior knowledge.

The outline of our article is as follows: We begin by describing different kinds of decisions along the cancer continuum from prevention (before a cancer has developed) to end of life (after curative options have been exhausted). Next, we discuss the reasons why people are not optimal decision makers, including instability of preferences, heuristics and biases, difficulties with affective forecasting, and widespread deficiencies in numeracy (the ability to use and understand numbers, such as risks and probabilities). As part of this discussion, we examine the implications of these findings for theories of decision making. Then, we review research on the effectiveness of aids to improve decision making and, thus, improve health outcomes, including emotional outcomes such as worry. In closing, we identify specific challenges and open questions that pertain to each of these aspects of decision making about cancer: what people make decisions about, how they decide, and how such decisions can be improved.

## Decisions Along the Cancer Continuum

The cancer continuum—prevention, screening, diagnosis, treatment, survivorship, and end of life—is a useful heuristic for thinking about cancer decisions because each phase has its own challenges. At the earliest phase—prevention—people face decisions with implications for cancer that occur far in the future, if they occur at all for a

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given individual. Nevertheless, half of all cancers could be prevented if individuals adopted healthy lifestyle behaviors, such as eating a healthy diet, eliminating tobacco use, and following recommended cancer screening and immunization guidelines (e.g., immunizing for hepatitis B to prevent liver cancer) (Green, Williams, Logan, & Strutton, 2011; Stein & Colditz 2004).

Adopting and maintaining these behaviors usually require an ongoing series of decisions carried out repeatedly over time. For example, smokers wishing to quit may have to reevaluate their decision to abstain multiple times a day. According to standard decision theory, people evaluate outcomes experienced with a new behavior and determine whether the behavior warrants continuing, which is a challenge when outcomes, such as cancer prevention, are long term (Rothman, 2000).

Like prevention, screening to detect cancer (or the risk of cancer) occurs before symptoms appear. Screening encompasses physical examination (e.g., clinical breast examination), laboratory tests (e.g., a blood test for prostate specific antigen [PSA]), imaging procedures (e.g., mammography), and genetic tests (e.g., BRCA1/2 mutations). Decisions about screening can be complicated by uncertainty about its benefits in prolonging life and the difficulty of weighing potential benefits and harms, such as harms following false positive results and overdiagnosis.

For example, because screening mammography in women 40 to 49 years of age was judged to have only a small net benefit, as of 2009, the U.S. Preventive Services Task Force (USPSTF, 2009) no longer recommended routine testing in this age group. However, they acknowledged that this decision “should be an individual one and take patient context into account, including the patient’s values regarding specific benefits and harms” (p. 716). This

change in screening recommendations for young women continues to be controversial (Webb et al., 2013), as was the later USPSTF decision to recommend against PSA screening, described as a “controversy that refuses to die” (Barry, 2009, p. 1351; see also Chou et al., 2011; Hartzband & Groopman, 2012; McNaughton-Collins & Barry, 2011; Moyer, 2012). According to standard decision theory, the usefulness of screening depends on the base rate of a disease (e.g., breast cancer prevalence is low for women in their 40s), the accuracy of the screening test, and the efficacy of treatment should cancer be detected.

Treatment decisions are complicated not only by uncertainty about their effectiveness and the balance of benefits and harms but by multiple potential outcomes that patients must consider. As the number and type of cancer treatment options have increased, patients and physicians face increasingly complex decisions. A patient may wish to weigh the costs and benefits of treatments with respect to duration of symptom-free survival, time spent with toxicity due to treatment, time to relapse, and impact on quality of life and functional status.

For example, active surveillance for men with prostate cancer involves invasive procedures, including PSA tests, digital rectal examinations, ultrasounds, and prostate biopsies (Cooperberg, Carroll, & Klotz, 2011; Tosoian et al., 2011). Although men who elect active surveillance avoid side effects of treatment, the psychological effect of living with the fear of cancer progression may create undue anxiety (van den Bergh, Korfage, & Bangma, 2012). This fear may explain why the vast majority of men with low-risk prostate cancer elect active treatment with surgery or radiotherapy, despite the risk of significant side effects (Fagerlin, Zikmund-Fisher, & Ubel, 2005).

Another important consideration involves the potential for long-term and delayed effects of treatment. For example, breast cancer patients considering adjuvant chemotherapy may be concerned about “chemobrain” and how cognitive dysfunction could affect future work and family life (Ganz, 2012). (Adjuvant therapy is given after primary therapy to increase the chance of long-term survival.) Patients may also have to decide about fertility preservation, a choice that sometimes must be made for children or adolescents, affecting future quality of life (Quinn et al., 2011).

Complicating these decisions, unaided affective forecasting, the ability to anticipate emotions and preferences, is poor for adults (Wilson & Gilbert, 2003) and even worse for children and adolescents (Nisker, Baylis, & McLeod, 2006; Reyna, Chapman, Dougherty, & Confrey, 2012). However, recent proposals to involve minors more in medical decision making, such as those about future fertility, have begun to build on developmental research in decision making (Wilhelms & Reyna, 2013). Also, as we discuss below, the purpose of decision aids is to help patients of all ages to better forecast their futures so that they can make informed decisions.

Cancer patients at the end of life face some of the most complex and difficult decisions of all. They must first recognize that they are entering the end of life—an emo-



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tionally challenging prognosis that is confounded by uncertainty—and then decide whether to pursue palliative rather than curative or life-sustaining goals. If they elect palliative care, they are then faced with deciding among a variety of interventions to ameliorate symptoms. As patients transition from curative to palliative care, they must decide where they want to spend their final days—at home, in hospice, in a nursing home, or in a hospital. With the emphasis on advance-care planning at the end of life, patients are asked to make difficult decisions early in the course of illness, well before death is imminent. Although this effort is ethically justified, it is also psychologically daunting given the difficulty of imagining unfamiliar and dreadful health states and formulating values and preferences for these outcomes. Therefore, decision research that shapes the context of these choices (e.g., by providing default options; Thaler & Sunstein, 2008) and decision aids grounded in such research have enormous potential to alleviate suffering, reduce uncertainty, and ensure that patients' wishes are followed about one of life's most crucial decisions.

### **Summary and Implications**

Ideally, decisions along the cancer continuum should be based on a full understanding of the benefits, harms, and uncertainties associated with alternative courses of action—an essential part of informed decision making (Rimer, Briss, Zeller, Chan, & Woolf, 2004). As the examples we presented illustrate, this ideal is difficult to achieve in cancer care, despite its ethical desirability. Cancer decisions often involve concepts that are hard to grasp, such as health risks and probabilities, technical medical information that is unfamiliar to most patients, and a multiplicity of options that can be overwhelming, especially in

the context of emotions, such as fear. In addition, decisions about prevention, screening, and treatment have repercussions for future quality of life, which is difficult to forecast. These challenges that are inherent in cancer decisions are compounded by the psychological limitations of individuals, which we explore in greater depth in the next section. The good news is that decision research offers insight into these challenges and limitations, with implications for how they can be addressed.

## **Why People Are Not Optimal Decision Makers**

In this section, we provide an overview of heuristics and biases that characterize decision making and explain how people respond to information about benefits, risks, and uncertainties. To begin, whereas uncertainty is a feature of decision making that is relevant across the cancer continuum (as we have discussed), a large body of research has shown that people find uncertainty aversive (e.g., Tversky & Kahneman, 1986). All other factors being equal, people prefer a sure or safe option over a risky one (known as “risk aversion”), sometimes so much so that they choose suboptimal treatments because they are perceived to be less “risky” (e.g., Fraenkel et al., 2012). People also have a preference against options involving unknown (ambiguous) versus known probabilities and respond to ambiguity by forming pessimistic judgments of risk and avoiding decision making—a response known as “ambiguity aversion” (Camerer & Weber, 1992; Ellsberg, 1961).

Ambiguity aversion has been demonstrated in multiple decision-making domains including cancer care. For example, the use of confidence intervals to communicate imprecision in risk estimates leads to elevated perceptions of environmental and health risks (Kuhn, 1997; Viscusi, 1997) as well as cancer risk (P. K. Han, Klein, Lehman, et al., 2011). Perceptions of ambiguity are associated with fatalistic perceptions about cancer prevention (P. K. Han et al., 2007; P. K. Han, Moser, & Klein, 2006), and the communication of ambiguity regarding the effectiveness of health-protective measures (Ritov & Baron, 1990; Viscusi, 1997), including cancer screening tests (Frosch, Kaplan, & Felitti, 2003; Volk, Spann, Cass, & Hawley, 2003), makes people less willing to adopt them. Nevertheless, ambiguity aversion is not a universal phenomenon; many people are ambiguity indifferent or even ambiguity seeking (Camerer & Weber, 1992), and some circumstances may promote ambiguity tolerance. For example, advanced cancer patients facing limited treatment options may view ambiguity about the expected benefits of treatment as a source of hope—suggesting greater outcome variability and the chance that a given individual could “beat the odds” (Gould, 1985; Innes & Payne, 2009).

Most scholars agree that informed decision making is more than uptake of information about benefits, risks, and uncertainties, however. Informed decisions should also be concordant with individuals' values and preferences (Rimer et al., 2004; USPSTF, 2009). The emphasis on patients' knowing their values and preferences has in-



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creased because patients are now in the driver's seat. That is, a growing movement referred to as "shared" or "patient-centered" decision making places more responsibility for decisions on patients, in interaction with their providers (Kaplan, 2004). Especially under conditions of "equipoise"—when the benefits of an intervention do not clearly outweigh the harms, or the strength of the evidence supporting an intervention is limited by substantial scientific uncertainty—the patient's values and preferences should be the determining factor in decisions (Elwyn, Frosch, & Rollnick, 2009).

According to standard decision theory, patients' choices reveal their values and preferences. However, heuristics (mental shortcuts) and cognitive biases produce inconsistent choices, making it difficult to infer patients' values and preferences. Indeed, contrary to standard theory, some scholars hold that "true" preferences often do not exist (Peters, Klein, Kaufman, Meilleur, & Dixon, 2013). In this view, rather than having preformed, stable values and preferences, people construct them in the moment of decision making, based on the available cues. When the cues change, choices change, producing inconsistency.

For example, consider choosing between two surgeries for colon cancer, each of which has an 80% cure rate without complications (Amsterlaw, Zikmund-Fisher, Fagerlin, & Ubel, 2006). An additional 4% of the people who have Surgery 1 survive but experience complications (1% colostomy, 1% chronic diarrhea, 1% bowel obstruction, and 1% wound infection); the remaining 16% die. In contrast, 20% of people who have Surgery 2 die. Although more than 90% of people surveyed preferred living with each of the complications over death, 49% chose Surgery 2 over Surgery 1. Clearly, this set of preferences is inconsistent. Many people who chose the surgery without compli-

cations chose it despite preferring life with complications over death. Effects such as this one, as well as many others exemplifying inconsistent preferences (e.g., framing effects, when treatment preferences shift depending on whether risks are described in terms of rates of mortality vs. survival; McNeil, Pauker, & Tversky, 1988), have prompted the inference that people do not have stable preferences.

Responses to the same numerical risk estimates also vary depending on the context of other numbers, a well-known perceptual comparison effect (i.e., the perceived magnitude of a stimulus depends on the magnitudes of other stimuli being evaluated; Windschitl, Martin, & Flugstad, 2002). These contextual effects are common in patients' evaluation of risks of cancer treatments (Zikmund-Fisher, Fagerlin, & Ubel, 2010). For example, when patients were asked to compare adjuvant therapies to prevent cancer recurrence, presenting the same increments in survival simultaneously as opposed to sequentially produced different preferences for therapy (Zikmund-Fisher, Angott, & Ubel, 2011).

Similarly, cutting the risk of recurrent breast cancer from 6% to 3% over five years with adjuvant therapy was viewed differently depending on whether the average risk was described as 3% or 12% (Fagerlin, Zikmund-Fisher, & Ubel, 2007). Specifically, women who were told that 3% is the average risk worried more about their greater-than-average 6% risk, whereas those told that 12% is the average risk were less worried about their lower-than-average 6% risk (Fagerlin et al., 2007). Not surprisingly, women in the 3% group were more motivated to undergo adjuvant therapy and were more convinced about its effectiveness, compared with those in the 12% group. In another study, patients given personalized risk estimates felt that those risks were high when they learned about the lowest risk levels for other women of their age and race (Lipkus, Biradavolu, Fenn, Keller, & Rimer, 2001). In addition, comparative information about average risk (which compares favorably to typical overestimation of personal risk) has been shown to reduce willingness to screen for cancer (see Fagerlin et al., 2005). Thus, elicited values, preferences, and risk perceptions about cancer fluctuate depending on the context of comparison.

These kinds of fluctuations in elicited judgments are more pronounced among people low in numeracy (Reyna, Nelson, Han, & Dieckmann, 2009). Those who are low in numeracy rely more on non-numerical information in decision making and are more susceptible to heuristics and biases, exhibiting more inconsistent values and preferences (e.g., Peters, McCaul, Stefanek, & Nelson, 2006). Although most scholars agree that numbers expressing the magnitudes of risks and of treatment outcomes should be provided to patients to achieve informed consent (Fischhoff, Brewer, & Downs, 2011), low numeracy is prevalent. More than 193 million Americans, estimated using a representative survey, lacked the quantitative proficiency needed for ordinary health-related tasks, such as calculating medication dosage for a child based on weight (Reyna et al., 2009). Hence, many patients cannot take advantage of the



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kind of numerical information needed for fully informed decision making.

As expected, complicated comparisons, such as those involved in adjuvant therapy, are particularly difficult for those lower in numeracy. Zikmund-Fisher, Fagerlin, and Ubel (2008) showed that about half of respondents to a survey could answer what they referred to as the most critical question about adjuvant therapy after viewing the standard risk information presentation using horizontal bars that compared four therapy options. The question was about incremental risk reduction achieved by adding adjuvant chemotherapy to hormonal therapy. The percentage of respondents correctly noting that two fewer women out of 100 would die—if they took chemotherapy combined with hormonal therapy—was improved by presenting a simpler two-option pictograph, but large differences remained for those differing in numeracy: For those higher in numeracy, 85% answered correctly with the two-option pictograph versus 62% with the four-option bar graph; for those lower in numeracy, 69% answered correctly with the two-option pictograph, compared to 43% with the four-option bar graph.

As we discuss below in the section on decision aids, values clarification methods are designed to reduce the impact of these cognitive problems by helping people deliberate about the attributes of options (e.g., risks) and how they map onto personal values. However, expert panels who have reviewed the literature have concluded that decision aids in general, and values clarification methods in particular, are not grounded in theory (e.g., Fagerlin et al., 2013). Therefore, these efforts to aid decision making are based on findings taken at face value or assumptions about decision processes, rather than scientifically established underlying mechanisms. We now turn to these mechanisms

in order to better understand how to explain, predict, and improve decision making about cancer.

## **Theories of Decision Making: Classical, Computational, Psychophysical, and Dual-Process Approaches**

The major mechanisms posited to explain decision making, listed in roughly chronological order of their emergence in the literature, fall roughly into five theoretical types: (a) classical, (b) computational (Simon, 1956), (c) psychophysical (Tversky & Kahneman, 1986), (d) those involving the dual processes of cognition versus emotion (or experience, Epstein, 1994), and (e) those involving fuzzy-trace theory's (FTT's) dual verbatim–gist representations, variable retrievability of values, and processing interference among overlapping event classes (Reyna, 2008). Elements of each of these approaches are reflected in current models of health decision making (e.g., Peters, 2012; Reyna, 2012b; Zikmund-Fisher, 2013).

As Simon (1956) pointed out, classical decision theory requires processing the probabilities and outcomes of all relevant options to make optimal choices, and a necessary condition for such optimality is that preferences be consistent. As we have discussed, however, actual choices are not optimal and preferences are not consistent. Therefore, Simon proposed a computational account of decision making that recognized people's information-processing limitations. Because of these limitations, people satisfied (or took mental shortcuts) rather than optimized.

To account for specific inconsistencies in preferences for risk, prospect theory was developed as a psychological account that distinguished between what people ought to do, described in classical theory, and what people actually do (Tversky & Kahneman, 1986). Prospect theory explained why increases in survival (gains) are not subjectively equivalent to decreases in mortality (losses), even when they are objectively equivalent. The theory built on the psychophysical functions of classical theory that translate objective quantities (e.g., years of life gained or lost) into subjective values, but with a steeper slope for losses than gains. Exact functions that translate objective into subjective values have been debated, but the basic idea that quantities are not perceived linearly (i.e., a constant numerical difference is not perceived consistently) has been upheld in many studies. For example, in the Amsterlaw et al. (2006) study presented earlier, people seemed to view a 0% versus 4% difference in complication rates as significant but dismissed an equally sized difference in death rates, 16% versus 20%, as negligible.

A major criticism of the computational and psychophysical approaches, however, has been that they did not incorporate emotion (e.g., Loewenstein, Weber, Hsee, & Welch, 2001). For example, when presentation formats equated numbers in the Amsterlaw et al. (2006) example by comparing 40 out of 1,000 patients with complications (Surgery 1) to 40 out of 1,000 who die from scar tissue (Surgery 2), in addition to the 160 who die from colon

cancer for both surgeries, 40% of people still preferred Surgery 2, a preference that was ascribed to emotion (e.g., see Zikmund-Fisher et al., 2010). In other words, complications such as colostomies and chronic diarrhea, as in the Amsterlaw et al. (2006) example, are assumed to elicit emotional responses that are at odds with the cognitive responses elicited by directly comparing each of these complications separately with death. Supporting the role of emotion in cancer decision making, as noted earlier in connection with the Fagerlin et al. (2007) study, women's worry reflected their subjective perceptions of risk as relatively low or high, despite being presented with objectively identical numerical values of 6% risk in different conditions of that study.

Dual-process approaches capture this conflict between emotion and cognition, sometimes characterized as experiential versus cognitive or as System 1 versus System 2 (Epstein, 1994; Peters, Lipkus, & Diefenbach, 2006). Zikmund-Fisher et al. (2010, p. S89) characterized the contrast as between "weighing risks and benefits [as in classical, computational, or psychophysical approaches] versus weighing feelings" (see also Peters et al., 2006). People experience integral emotions about cancer, notably fear, anger, and sadness, but they also experience incidental emotions, which arise in unrelated situations and carry over to health contexts. Incidental emotions are irrelevant (by definition) to health decisions, but these emotions have been shown to shape risk perceptions, especially for those low in numeracy, for whom numerical expressions of risk have little meaning (Peters, 2012).

In sum, classical, computational, and psychophysical approaches to decision theory emphasize the trading off of harms, benefits, and uncertainties (e.g., Brewer & Rimer, 2008). Thus, if the risks of screening are low and the benefits are high, these approaches predict that people would choose screening—with caveats based on such mediators as self-efficacy, perceived control, or perceived barriers (e.g., Brewer et al., 2007; Fishbein, 2008; Prochaska, 2008). However, these approaches have been criticized as too cognitive; they omit emotion as an explicit factor in decision making (Loewenstein et al., 2001; McCaul, Peters, Nelson, & Stefanek, 2005).

Addressing this gap, dual-process models initially emphasized opposing effects of cognition and emotion. For example, in addition to the examples mentioned earlier of opposing effects of cognition and emotion, Rini et al. (2009) contrasted cognitive versus emotional effects on decisional conflict after patients received an ambiguous (indeterminate) BRCA1/2 test result (the BRCA1/2 test identifies genetic mutations that increase breast and ovarian cancer risk): Cognitive factors (health beliefs) were more important in predicting decisional conflict one month after test disclosure, but emotional factors were more important one year later. Summarizing the literature, Zikmund-Fisher et al. (2010) concluded that emotions are often more influential than factual knowledge in decision making about cancer treatments and prevention.

## **Beyond Opposing Dual Processes of Cognition Versus Emotion**

We have thus far emphasized contrasting effects of emotion versus cognition, which have been used in the past to justify assuming that there are dual processes in decision making. However, current theories generally acknowledge that emotion and cognition can be complementary (e.g., Wood & Bechara, 2014, and see below). That is, integral and incidental emotions need not conflict with objective appraisals of risk or other health-related valuations and can facilitate decision making. For example, the fact that anger increases risk taking (as predicted by the appraisal tendency framework) may benefit a decision maker when the option associated with the best medical outcome is risky, as is the case with some treatments for cancer (Ferrer, Klein, Lerner, Reyna, & Keltner, in press). Although the appraisal tendency framework is not a theory of decision making *per se*, it augments dual-process approaches by supplying specific mechanisms with which to understand how decisions may benefit from, or be hindered by, discrete emotions (S. Han, Lerner, & Keltner, 2007; Lerner & Tiedens, 2006).

Although the likely effects of emotion on cancer decision making—good and bad—are undeniable given the extant literature, some important effects are attributed to emotion that, instead, may be cognitive in origin. Surprisingly few studies have manipulated emotions experimentally to determine their effects on risk perceptions (but see Johnson & Tversky, 1983, for an exception). The affect heuristic, for example, has been invoked to explain such effects as judging risk as larger when it is described using frequencies (e.g., "Of every 100 patients similar to Mr. Jones, 10 are estimated to commit an act of violence . . . after discharge") than when it is described using percentages (10% in our example; Slovic, Peters, Finucane, & MacGregor, 2005). However, there is little evidence that this effect is affective or emotional other than that more vivid images were reported in the frequency condition than in the percentage condition. Naturally, more vivid imagery could be the *result* of a higher perception of risk of violence, as opposed to a *cause* of a higher perception of risk of violence. Indeed, this frequency–percentage effect is easily explained by prior theories of denominator neglect that have been tested with experimental designs (the denominator of 100 is neglected relative to the numerator of 10 in the frequency formulation, but 10% has no explicit denominator to neglect; Reyna, 2004).

Similarly, Denes-Raj, Epstein, and Cole's (1995) ratio-bias finding has been attributed to affective or emotional responses (e.g., Peters et al., 2006; Zikmund-Fisher et al., 2010) but is predicted by cognitive theory without appealing to affect or emotion (e.g., Reyna & Brainerd, 1994, 2008). The ratio-bias effect is evident when people "feel" that a bowl with 9 red jelly beans out of 100 gives them a better chance of winning a red bean because it contains a larger number of red beans, despite "knowing" that a bowl with 1 red bean out of 10 gives them the best chance of winning. Treatment decisions involving survival and mortality rates are subject to this ratio-bias effect (e.g.,

Garcia-Retamero & Galesic, 2009). (The ratio bias has also been called the “numerosity effect” because the relative numerosity of numerators, 9 versus 1 in our jelly beans example, takes precedence over the ratio of numerators to denominators; Reyna & Brainerd, 1994). Although the ratio-bias result is a critical prediction of cognitive-experiential theory (Epstein, 1994), valid and reliable measures of cognitive versus experiential thinking have repeatedly failed to correctly predict this bias, raising doubts about the affective explanation (for a review of evidence, see Reyna & Brainerd, 2008).

Thus, in addition to bona fide effects of emotion that must be captured by theory, cognition is sometimes sufficient to explain effects attributed to emotion, and other times it produces an emotional response that, in turn, influences decision making (e.g., Reyna, 2008; Reyna & Rivers, 2008). Past criticisms of cognitive approaches were directed at classical, computational, or psychophysical theories, but these specific criticisms do not apply to newer representational or meaning-based cognitive approaches that incorporate emotion and motivation (for a review of newer theories, see Reyna & Rivers, 2008).

Distinguishing among theoretical mechanisms in specific instances (e.g., whether cognitive or emotional factors, or both, explain an effect) is important for understanding and facilitating cancer decision making. To illustrate, Schnur et al. (2006) found that an observed relationship between family history and prostate cancer worry was fully mediated by perceived prostate cancer risk. A reversed causation model, in which worry led to increased perceived risk, was a poor fit to the data. In other words, these results are consistent with perceived risk (a cognitive factor) causing worry (an affective or emotional factor) rather than the other way around. These results suggest that reducing worry or anxiety may not always be a suitable goal for decision aids (e.g., better to target perceived risk in order to reduce worry, according to this study). In fact, based on a review of the literature on decision aids, Bekker, Légaré, Tracey, O’Connor, and Lemyre (2003) concluded that moderate levels of anxiety may facilitate effective decision strategies about screening and treatment.

Rather than viewing cognition and emotion as opposing processes, current dual-process theories generally take an integrative approach (de Vries, Fagerlin, Witteman, & Scherer, 2013; Peters, 2012; Reyna, 2012b; Schmiede, Bryan, & Klein, 2009; Zikmund-Fisher, 2013). We have already discussed many assumptions of these theories, but we now briefly introduce fuzzy-trace theory, which brings together concepts concerning mental representation (verbatim vs. gist), emotion, social and moral values, and class-inclusion confusion (reflected in ratio bias, the frequency–percentage effect, and misunderstanding of conditional probabilities, such as the probability of a BRCA mutation conditioned on having had breast cancer).

### **An Alternative Dual-Process Approach: Fuzzy-Trace Theory**

Fuzzy-trace theory (FTT) is a dual-process approach that has been applied to a wide array of health and medical decisions, including cancer decision making (e.g., Brewer, Richman, DeFrank, Reyna, & Carey, 2012; Dawson, Johnson, & Luke, 2012; Hutton, Belkora, Shacter, & Moore, 2009; Reyna, 2008; Reyna, Lloyd, & Whalen, 2001). The theory’s predictions have been tested in many experiments with diverse populations, and its assumptions have been formalized in mathematical models of memory, judgment, and decision making (Kühberger & Tanner, 2010; for overviews, see Reyna, 2012a; Reyna & Brainerd, 1995, 2011). The theory builds on prior approaches, but, unlike those approaches, it distinguishes two kinds of mental representations of information: verbatim and gist.

Verbatim representations are encoded in parallel with gist and capture the surface form of information—the exact words, numbers, or pictures. This precise form of representation lends itself to supporting precise analysis, such as rote computation (e.g., dividing exact numbers mechanically, regardless of their meaning or relevance to the task; Liberali, Reyna, Furlan, Stein, & Pardo, 2012; Peters, Västfjäll, et al., 2006; Reyna et al., 2009). In contrast, gist representations capture the essential meaning of information, which is shaped by emotion, knowledge, culture, context, and worldview, among other factors. Gist representations support the fuzzy, parallel, usually unconscious processes of intuition (defined as in the foundations of mathematics). Evidence for specific kinds of gist representations and for specific types of processing (e.g., unconscious use of gist) has been gathered by testing models of numerical and verbal information processing (e.g., Reyna, 2012a; Reyna & Brainerd, 1995).

Typical gist representations of information that are used in medical decision making include (a) categorical gist (e.g., safe vs. risky; save some lives vs. no lives), (b) ordinal gist (e.g., low vs. high risk; save more lives vs. fewer lives), and (c) linear-ordering gist that integrates multiple items and roughly orders them (e.g., toward the low vs. high end of risk among a set of medications; localized “in situ” cancer vs. stages of metastasizing to other organs) (e.g., Brewer et al., 2012; Fraenkel et al., 2012; Reyna & Brainerd, 1995). Applying these distinctions among representations (e.g., categorical possibility, ordinal or relative possibility, absolute or verbatim probability) that were introduced in laboratory tasks involving probability judgment and decision making, Zikmund-Fisher (2013) illustrated how such mental representations apply more broadly to medical decision making.

Thus, when presented with any meaningful information (e.g., on the Web or in a doctor’s office), people routinely extract the gist of individual items (e.g., words or numbers), combinations of items (sentences and inferences), and extended narratives. A major difference between gist and alternative verbatim representations is that gist captures a functionally significant bottom line that

integrates and interprets information, often through causal inferences, as opposed to being a list of arbitrary facts.

As can be gleaned from this discussion, the definition of gist in FTT differs sharply from the traditional definition of heuristics as “strategies that ignore information to make decisions faster, more frugally, and/or more accurately than more complex methods” (Gigerenzer & Gaissmaier, 2011, p. 453). Gist is not defined simply as processing less information. Gist involves understanding meaning (insight in the gestalt sense)—integrating dimensions of information to distill its essence, not just processing fewer dimensions of information that are “good enough” (Reyna, 2013). The degree of insight captured in a gist representation depends on specific characteristics of the individual (e.g., background knowledge; Reyna, Chick, Corbin, & Hsia, 2014; Reyna & Lloyd, 2006).

Although people encode verbatim and gist representations, they generally have a fuzzy processing (gist) preference for familiar information; they begin with the simplest level of qualitative representations—categorical—but engage more precise representations (e.g., ordinal, such as lower vs. higher risk) if that is required to discriminate options. (Zikmund-Fisher’s, 2013, taxonomy of appropriate levels of precision in patient risk communication corresponds to FTT’s concepts of hierarchies of gist and task calibration; see Reyna & Brainerd, 1994, 1995.) Thus, the categorical possibility of a bad outcome tends to produce risk aversion (preference for safer options), all other factors being equal, because people do not precisely trade off risks and benefits; they *encode* trade-offs but *decide* based on gist, such as a categorical possibility.

Once options are represented, people retrieve relevant values and principles, such as social norms and moral principles (e.g., for health, family, saving lives, and so on; Fukukura, Ferguson, & Fujita, 2013; Reyna & Casillas, 2009). According to FTT and consistent with evidence, values are stored in long-term memory as vague gists and are retrieved as opposed to constructed. Retrieval is variable because it depends on cues or reminders (even when values are deeply held; for one detailed retrieval model, see Brainerd, Reyna, & Aydin, 2010). When retrieved, people apply these values and principles to the gist representations of their options to produce choices (Reyna, 2004, 2012b). Thus, choice variability stems from changes in wording that evoke different mental representations (e.g., the gist of “some survive” differs from that of “some die” even when they refer to the same objective number), differences in retrieval cues for values and principles, and difficulties associated with mapping stored values onto representations of information. Each of these factors—representation of options, retrieval of values or principles, and mapping of values onto representations of options—accounts for unique variance in decision making (e.g., Reyna, Lloyd, & Brainerd, 2003).

For example, some asymptomatic low-risk people have been found to be averse to screening for cancer because the gist of the options for them boils down to “being okay,” which is the status quo, versus “getting screened and discovering either that one is okay or not

okay.” Because cued values favor being okay over not being okay, they prefer to not be screened (Reyna, 2008, 2012b). In this view, the line between “okay” and “not okay” in a patient without cancer is ultimately psychological (although objective information figures into the determination of this threshold). According to this explanation, patients who view the risks of screening as non-nil (i.e., as taking “some risk” of being “not okay”) mentally cross a categorical line between being “okay” to potentially being “not okay” as their status quo in order to choose screening.

The application of values/principles to representations can be disrupted by noise, strong emotion, or forms of cognitive interference, such as partially overlapping or nested classes in probability judgments—called class-inclusion interference (Reyna, 1991; Reyna & Brainerd, 2008). For example, the class of people with genetic risks overlaps with the class of people who have (or will develop) the disease of invasive breast cancer. For Huntington’s disease, the overlap is complete; having the genetic mutation means that the disease will develop, and vice versa. This class structure is easy to process (Reyna et al., 2001). The partially overlapping class structure for BRCA1/2 mutation is difficult to process (e.g., Hanoch, Miron-Shatz, & Himmelstein, 2010): Most people with breast cancer do not have the mutation, but most people with the mutation develop breast cancer, a confusing relationship. According to FTT, this confusion results in denominator neglect as people focus on target classes, neglecting the more inclusive classes in which targets are contained. Interventions designed to segregate overlapping classes reduce denominator neglect, thereby considerably reducing biases and fallacies in probability judgment, a beneficial effect demonstrated in subjects ranging from students to physicians (e.g., Lloyd & Reyna, 2001; Wolfe & Reyna, 2010).

The topic of emotion is no longer neglected in most modern theories of decision making. Research on FTT and research on emotion have been integrated, for example, in the concept of “emotional gist” (Brainerd, Stein, Silveira, Rohenkohl, & Reyna, 2008; Rivers, Reyna, & Mills, 2008; Zikmund-Fisher et al., 2010; see also affective meaning, Peters, 2012). Emotional gist is a mental representation that incorporates emotion as part of meaning. Emotion can be further specified in terms of mood or the valence of content, which have distinct effects on how information is processed. For example, negative mood produces greater attention to verbatim details (e.g., cancer worry was associated with greater attention to details; Beckjord, Finney Rutten, Arora, Moser & Hesse, 2008), whereas negative content produces greater attention to gist (e.g., Brainerd et al., 2008; Rivers et al., 2008). As discussed early in the development of FTT (grounded in the pioneering work of Zajonc, 1980, and Isen, 1997), valence (good–bad) is a simple gist. Memory for valence is retained over long periods, supporting the conclusion that it is represented as gist (if valence were represented in verbatim memory, it would fade quickly). That is, the emotional essence of an experience is retained and, as models of recall show, can be used later to reconstruct details (Gomes, Brainerd, & Stein,

2013; Reyna, 2011). Valence and also discrete emotions (e.g., fear, anger, happiness, and so forth) act as organizing themes for recalling the past and extrapolating to the future (Rivers et al., 2008).

## **Decision Support in Cancer Care**

Thus far, we have reviewed cancer decisions across the continuum from prevention to end of life, heuristics and biases that make decisions inconsistent, and theoretical explanations of the mechanisms of those decisions. This discussion has touched on research about cognition, emotion, social values and principles, and informed decision making. In the following section, we review research on decision support, namely, how evidence-based practices can facilitate decision making about cancer. Although decision support includes training of providers, counseling and training of patients, and use of patient decision aids, we focus on aids because they have the largest and strongest evidence base. As we noted earlier and is evident from our review, most decision support has been designed without specific grounding in theory. In the section that follows, we discuss how these literatures can inform one another and the challenges of improving decisions relevant to cancer.

### **Cancer-Related Decisions Are Complex and Can Benefit From Decision Support**

Prevention and treatment of cancer are particularly good targets for decision support for several reasons. First, as noted earlier, cancer accounts for a significant amount of morbidity and mortality. Second, fear of cancer is high among the general public, and perception of cancer risk often exceeds its true level. Third, the options for cancer prevention, screening, and treatment are growing in number and complexity. That is, as we have discussed, differences among options may be uncertain and difficult to understand for the average patient.

In addition, because cancer diagnoses, or fear of a cancer diagnosis, produce considerable emotional impact, as we have also discussed, decision-making processes are likely to be affected. Also, cancer decision making often requires affective forecasting about unfamiliar courses of action and is subject to heuristics and biases (see the section *Why People Are Not Optimal Decision Makers*). Finally, cancer remains a taboo subject for many patients, and discussion of cancer-related treatment options may be difficult for patients and providers alike. Thus, having support for cancer-related decision making can be particularly beneficial.

### **Cancer-Related Decision Aids Have Been Developed and/or Evaluated for Efficacy**

Many decision aids are available, but fewer have been evaluated in efficacy or effectiveness trials. A search of the Ottawa Decision Aid inventory (<http://decisionaid.ohri.ca>) using the keyword *cancer* identified 47 different decision aids on cancer screening, prevention, and treatment topics. The most recent Cochrane review of decision aids (Stacey et al., 2011) identified 86 trials: Cancer-related decisions

were examined in 38 of the 86 trials (44%). Prevention or screening decisions were most common ( $n = 29$ ), with fewer trials examining treatment ( $n = 8$ ) or survivorship issues ( $n = 1$ ). The most common decision addressed was PSA screening ( $n = 11$ ); colon cancer screening was addressed in 5 studies (Stacey et al., 2011). Notably, most of the decision aids identified in the search of the Ottawa database have not been evaluated in randomized trials; conversely, many of the decision aids tested in trials were not identified in the Ottawa database.

### **Decision Aids Improve Some Decision-Making Outcomes**

The full Cochrane review found decision aids (for all topics) to be effective in improving knowledge, creating more realistic outcome expectations, reducing decisional conflict and uncertainty, and possibly improving physician–patient communication, compared with no decision aid. Health outcomes did not appear to be affected; adherence and cost outcomes were too few in number to be evaluated (Stacey et al., 2011).

Results for cancer-specific decisions were not examined as a separate group. However, the Cochrane reviewers found that those receiving a PSA decision aid were less likely to receive screening than those receiving usual care (relative risk [RR] = 0.85, 95% CI [0.74, 0.98]; Stacey et al., 2011). For colon cancer screening, the effect of decision aid use on screening was mixed, and the summary estimate of effect was imprecise (RR = 1.20, 95% CI [0.90, 1.61]). There were too few trials to draw firm conclusions about the effects of decision support on cancer surgical options. One trial found no effect on preferences for adjuvant chemotherapy in breast cancer (Whelan et al., 2003). Thus, it appears from the recent Cochrane review that decision aids generally improve decision-related outcomes (knowledge, risk perception, decisional conflict), but the effects on more distal outcomes are mixed or uncertain, due to a relatively small number of trials.

### **Specific Elements of Decision Aids That Produce Improved Outcomes Are Not Clear**

Many questions remain about which elements should be included in decision aids. On the one hand, developers of decision aids want to provide all the information and tools that a patient may need, such as values clarification tools. On the other hand, too much information may overwhelm or confuse the patient (particularly in the case of a new cancer diagnosis), risks the possibility that the patient will miss the key information while sorting through less important information, and may make the decision aid difficult to administer in clinical practice (Peters et al., 2013; see also Bastardi & Shafir, 1998).

Despite guidelines for decision aid development and evaluation (Elwyn et al., 2006), the decision to include or exclude certain elements in decision aids typically requires empirical testing, as prior research and expert opinion could support either decision. As an example, one question that arose in the development of a decision aid for colon cancer screening was whether the option of “no screening”

should be offered as a “legitimate” choice. The investigators conducted a trial in which patients were randomized to view a decision aid with or without a segment in which the option of no screening was discussed (in a balanced manner). The proportion of viewers interested in screening did not differ, but the version without the “no screening” option was perceived as more favorable toward screening and clearer (Griffith, Fichter, Fowler, Lewis, & Pignone 2008).

Another question is whether decision aids should include an explicit tool to help users consider their personal values and relate them to elements of the decision. These “values clarification tools” can include simple advice to “think about what aspects of this decision are most important to you” to explicit tasks such as rating, ranking, or even discrete choice experiments. A multidisciplinary group (including Valerie Reyna and Michael Pignone) reviewed the effect of including values clarification in decision aids and identified 13 trials that compared decision aids with or without explicit values clarification tools; of these, six involved cancer-related topics (Pignone et al., 2012). Some studies suggested improvements in decision processes or outcomes, but overall there were no clear, consistent effects.

## Conclusions and Implications for Future Research

### Summary and Overview

As this survey of research shows, decisions across the cancer continuum tap processes that are subject to cognitive limitations, such as heuristics and biases, and these limitations are more evident for some concepts (e.g., risk and ambiguity) and for some individuals (e.g., people low in numeracy) than others. In addition, cognition and emotion can conflict, undermining optimal health outcomes (e.g., watchful waiting rather than prostate surgery in some older men with slow-growing cancers), but recent research has identified points of synergy, for instance, the potential effect of anger on lowering risk perceptions of needed treatments.

Theoretical and empirical advances suggest that decisions that ignore such emotional factors as anxiety and dread are likely to reduce patients’ quality of life. However, it is also true that patients can regret irrevocable decisions (e.g., surgery) made in a moment of panic, once they have adapted to the initial news of cancer and dispassionately considered their options. Affective forecasting—the ability to forecast emotions into the future (especially in unfamiliar situations such as a cancer diagnosis)—is notoriously poor. Therefore, emotions are not an unalloyed “good,” the secret to wisdom in an overly intellectualized world, nor are they a factor that should be ignored in considering the best decision for a given patient. In fact, new concepts such as emotional gist suggest that informed decision making may someday take advantage of emotional processing to guide patients to better extrapolate from their past experience to foresee their affective future with cancer, facilitating their decision making. Research is urgently needed on

the precise loci of interactions between emotion *and* cognition to improve cancer decision making.

Although empirical phenomena relevant to cancer decision making have informed theories, these evidence-based theories have not become the basis for decision aids, despite their clear relevance. In concert with other groups, we see this lack of theoretical grounding as a major shortcoming of decision aids, one that explains in large part why it is not known which elements of decision aids might be effective—and research should be focused on this problem. To that end, we briefly describe testable implications of a contemporary integrative theory of health and medical decision making.

### Implications of FTT for Decision Support Interventions in Cancer Care

FTT has several important implications for the development of decision support interventions aimed at enabling informed decision making and shared decision making in cancer care. Above all, it suggests a different approach from interventions based on classical and traditional dual-process theories of decision making, which grant primacy to deliberative processing of precise quantitative (verbatim) information. Unlike these other approaches that stress an evenhanded list of detailed risks and benefits (e.g., listing the pros and cons of surgery, as is typical for decision aids), FTT suggests that decision support should strive to capture the *essential bottom line* of patients’ options, resolving trade-offs to the degree that is possible. Decision support, therefore, should “begin with the end in mind” by identifying the key gists of the information to be conveyed, which can be obtained by surveying experts and experienced patients (Fraenkel et al., 2012).

Until recently, a common measure of risk perception has been to ask people for a number that corresponds to the probability that an adverse event would occur. “Understanding” risk was then measured as agreement between objective (or presented) numbers and reported numbers. Nowadays, applying the FTT distinction between verbatim versus gist measures of risk, investigators recognize the shortcomings of such verbatim measures (e.g., Gaissmaier, Skopec, Müller, Broschinski, & Politi, 2012; Hawley et al., 2008; Peters et al., 2009; Tait, Voepel-Lewis, Zikmund-Fisher, & Fagerlin, 2010; Tait, Zikmund-Fisher, Fagerlin, & Voepel-Lewis, 2010). Parrotting back a numerical risk or reading a number off a bar graph without an appreciation of what the number means falls short of informed decision making (Peters, 2012; Reyna, 2008; Reyna et al., 2009; Zikmund-Fisher, 2013).

In this view, informed decision making is not accomplished by recalling or recognizing rote facts (e.g., identifying, based on a graph, exactly how many patients in a treatment group are alive after five years; Lipkus, Peters, Kimmick, Liotcheva, & Marcom, 2010; Weinfurt et al., 2003), which are rapidly forgotten in any case (Sepucha et al., 2013). Misremembering the risk of death from surgery as 10% (when it is actually 2%) is superior, from a gist perspective, than misremembering it as zero, although 0% is numerically closer to the true value of 2% (Reyna &

Hamilton, 2001). In this instance, informed consent consists of recognizing that there is *some* (small) risk of death from surgery (i.e., communicating the categorical possibility of death; P. K. Han, Klein, & Arora, 2011). Similarly, informed decision making consists of recognizing *some* ambiguity surrounding estimates of risk—without losing the gist that some risks are higher than others. In fact, recent research based on FTT has shown that estimating a range of potential probabilities (which acknowledges ambiguity), rather than a point estimate, reduces biases (Brown, Nowlan, Taylor, & Morley, 2013). The critical goal is to communicate the gist of ambiguity in a manner that minimizes *unreflective* aversion by helping patients understand not the exact endpoints of a confidence interval, but the bottom-line message that ambiguity applies to risk estimates—that their true risk is not known with the precision that a point estimate implies (P. K. Han, Klein, Lehman, et al., 2011).

More generally, as shown in psycholinguistic research, multiple gist interpretations of the same information exist and are usually encoded. Thus, informed decision making usually involves encoding several key qualitative facts, for example, that there is risk and ambiguity and that risks and benefits trade off, but, nevertheless, that one treatment far exceeds another in benefits (Tait et al., 2010). In most situations, the number of alternative gist representations is small and predictable for people with similar background knowledge. However, these representations cannot be reduced to a rote formula—such as assigning the same labels to identical probabilities. The meanings of, say, a 20% chance of rain (low) and a 20% chance of invasive cancer (high) differ greatly (Reyna, 2013). A major gap in research that emerges from this analysis is to establish principles and best practices for gist extraction in cancer decision making, including their measurement and evaluation.

In sum, FTT suggests that decision support interventions for informed decision making should (a) ensure that patients understand the essential gist meaning of information (which is not the same thing as presenting less information), (b) remind patients of an array of simple social and moral values that are important to them and that have relevance to the decision at hand (because even strongly held values are not necessarily retrieved), and (c) assist patients in applying their values to their mental representations, ensuring that overlapping sets are disentangled (Bartels, Bauman, Skitka, & Medin, 2009; Reyna, 2008; Reyna & Lloyd, 2006).

Future research should focus on integrating evidence-based principles from multiple theoretical perspectives to discover how semantic and contextual factors shape patients' perceptions of the gist of information (e.g., categorization of risk as low vs. high); how patients' understanding of evaluative categories (e.g., outcomes of treatments as good vs. bad) can be supported; how values can be elicited that are stable and that reliably map onto future well-being; and how these processes differ across individuals and age groups that reflect the changing demographics of decision makers.

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