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*J Behav Med.* 2017 February ; 40(1): 52–68. doi:10.1007/s10865-016-9785-z.**What is a good medical decision? A research agenda guided by perspectives from multiple stakeholders**

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## Abstract

Informed and shared decision making are critical aspects of patient-centered care, which has contributed to an emphasis on decision support interventions to promote good medical decision making. However, researchers and healthcare providers have not reached a consensus on what defines a good decision, nor how to evaluate it. This position paper, informed by conference sessions featuring diverse stakeholders held at the 2015 Society of Behavioral Medicine and Society for Medical Decision Making annual meetings, describes key concepts that influence the decision making process itself and that may change what it means to make a good decision: interpersonal factors, structural constraints, affective influences, and values clarification methods. This paper also proposes specific research questions within each of these priority areas, with the goal of moving medical decision making research to a more comprehensive definition of a good medical decision, and enhancing the ability to measure and improve the decision making process.

## Keywords

decision making; shared decision making; decision quality; patient-centered care; physician-patient communication; patient participation

## Introduction

The Institute of Medicine identified patient-centered care as a critical component of healthcare quality (Institute of Medicine, 2001). Patient-centered care “is respectful of and responsive to individual patient preferences, needs, and values, and [ensures] that patient values guide all clinical decisions.” This principle extends beyond what is traditionally referred to as informed consent; it emphasizes that enabling patients to become active participants in making decisions about their healthcare, particularly via a process of shared decision making when decisions lack a clear evidence-based “right” choice, involve the consideration of both benefits and harms, or are clouded by conflicting expert recommendations and rapidly changing evidence, can result in more informed decisions and better quality of care.

One consequence of this increased emphasis on informed and shared decision making is growth in the development and testing of interventions that aim to foster good medical decision making by patients and healthcare providers (i.e., decision support interventions). However, researchers and healthcare providers continue to struggle with defining the necessary conditions or indicators of a good medical decision, and how to evaluate whether a good decision has been made (Elwyn & Miron-Shatz, 2010; Ratliff et al., 1999). Yet, to be effective, such interventions need to be guided by a clear operational definition of a good medical decision and have valid and reliable measurement approaches consistent with that definition. Achieving consensus on the definition of a good medical decision would

overcome a critical barrier to developing highly effective decision support interventions and would advance the science of medical decision making more generally.

As one step toward achieving greater clarity in conceptualizing how a good medical decision can be defined, measuring attainment of this goal, and ultimately helping people to make good medical decisions, members of the Society of Behavioral Medicine (SBM) Health Decision Making Special Interest Group and the Society for Medical Decision Making (SMDM) developed two complementary “crosstalk” sessions for the 2015 SBM and SMDM annual meetings titled “What is a ‘Good’ Medical Decision? Perspectives from Multiple Stakeholders.” Both sessions were highly interactive, attracted attendees from many disciplines, and featured representatives from key stakeholder groups invested in identifying and promoting good medical decision making: physicians, patients, insurance companies, decision scientists, and medical anthropologists.

In each session, stakeholders and audience members discussed case scenarios involving complex, contemporary medical decisions (see Supplementary Material) including the management of uncertain incidental findings identified through genomic sequencing; end-of-life decision making with surrogate decision makers and complicated family dynamics; the cessation of colorectal cancer screening in older patients; and the use of surgery for low-grade ductal carcinoma in situ of the breast. These discussions identified a number of important themes and critical gaps in scientific knowledge relevant to identifying good decision making. The conference sessions were audio-recorded and/or transcribed, and there were dedicated note takers. After both sessions had concluded, the planners of the conference sessions and participating stakeholders reviewed the audio-recordings and/or session transcripts and notes to identify the most salient topics. This paper describes key concepts and research needs that the co-authors recognize as pressing in the field. We first offer a brief summary of current knowledge about what constitutes a good patient-centered medical decision, and identify potential gaps in the definition of a good decision. We then discuss selected priority areas for future inquiry that stem from the conference sessions and the unique perspectives of the various stakeholders, and make recommendations about which research questions need to be examined in order to develop a more comprehensive understanding of good medical decisions.

## Decision Making Research: General Background

Good medical decisions are most difficult to define in situations that are characterized by uncertainty and that lack an agreed upon “right” choice. Such situations are common in healthcare, where, despite an emphasis on evidence-based medicine, patients and providers frequently encounter complex decisions that lack adequate evidence or expert consensus to guide the selection of a particular option. Currently in such decision contexts, good medical decisions are often defined in three ways. First, that the process is good, in the sense that the decision is made with a consideration of factual and probabilistic health information, along with personal values and preferences (Sepucha et al., 2004). Ideally, this evaluation process is conducted using a shared decision making approach. Shared decision making requires that patients: 1) recognize that a decision needs to be made; 2) understand the features, risks, and benefits of available treatment options; 3) consider personal goals and preferences to

determine which treatment options are aligned most closely with their values; 4) are meaningfully involved in the decision making process with their healthcare provider (including expressing the desire to not participate further, when such a desire exists); and 5) arrive at a medical decision that is based on what is known about the options and is consistent with their values and preferences (i.e., a “value-concordant” decision; O’Connor et al., 2005; Stacey et al., 2014; Volk & Llewellyn-Thomas, 2012).

The second way that a good medical decision is defined is in the sense that the outcomes of the decision are good. These outcomes include the extent to which patients obtain a value-concordant treatment, experience limited regret about the decision process and outcome, and are satisfied with the decision experience (Holmes-Rovner et al., 2007; Sepucha et al., 2013; Stacey et al., 2014). Although a good decision outcome could also involve a good health outcome (e.g., recovery from surgery without complications), having a good health outcome is not a required element (Elwyn & Miron-Shatz, 2010). For example, a patient who experiences a rare but severe surgical complication could be said to have engaged in a good decision process, if that decision was based on an informed decision making process and the patient experienced high satisfaction about the decision.

A third way of defining a good decision has been driven primarily by an economic or decision-analytic model of decision making. Specifically, that a good decision maker *should* focus on expected value, balancing the objective probabilities associated with different aspects of different options, and the extent to which each of those aspects is desirable (i.e., expected utility theory; von Neuman & Morgenstern, 1947). This perspective is reflected in medical decision making research via its emphasis on combining detailed probabilistic information about the risks and benefits of treatment options with personal values and preferences (i.e., desirability of outcomes), and then choosing the option that is most value-concordant.

However, this is not the way most people make real decisions (J. Ryan & Sysko, 2007; S. K. Smith et al., 2009). Instead, we experience the world through lenses that distort objective probabilities in predictable ways (i.e., cognitive biases; Tversky & Kahneman, 1974). For example, people tend to focus primarily on the number of people affected by a hazard (i.e., the numerator), rather than placing this number in the context of the total number of people in the overall population (i.e., the denominator). This tendency commonly results in higher risk perceptions for a hazard described as affecting 1,286 out of 10,000 people than 24.14 out of 100 people (Yamagishi, 1997). Another challenge to the economic model of decision making is that, in general, preferences about treatment options (and other issues) are constructed and labile rather than pre-existing and stable (Slovic, 1995). Simple changes to the way a treatment option is framed can drastically alter its desirability (McNeil et al., 1982). Furthermore, the economic perspective does not account for past personal experience in decision making, nor the fact that decision makers are influenced by considerations at multiple levels of social influence, including the interpersonal level (e.g., family), organizational level (e.g., paid leave from work), community level (e.g., availability of specialty care within easy traveling distance), and policy levels (e.g., national policies regarding healthcare payment and reimbursement).

## Decision Making Research: Conceptual Frameworks

One of the earliest conceptual frameworks intended to address some of these realities and inform the development and evaluation of interventions for promoting good decision making is the Ottawa Decision Support Framework (O'Connor et al., 1998). According to this framework, decision quality is determined by having a good decision process (including engagement in shared decision making) and a good decision outcome (in the sense described above). This framework assumes that decision making is a multi-dimensional process that is affected by: specific characteristics of the decision (e.g., the urgency of the decision); decisional conflict (e.g., uncertainty about the course of action); knowledge and expectations of the health situation and treatment options and outcomes; personal values and preferences; support and resources needed to make and implement the decision at multiple levels of influence (e.g., family opinions, financial support, interest in making a decision); personal characteristics (e.g., age, gender); and clinical characteristics (e.g., education, counseling style).

This paradigm has been used to develop many decision support interventions, including decision aids, that are designed to help people participate in medical decisions (i.e., improve process) and to improve decision outcomes. These interventions often consist of electronic or paper-based tools that patients can use before or during a discussion with their healthcare provider. International standards, grounded in the principles of shared decision making, call for decision aids and other decision support interventions to: provide balanced information about the risks and benefits of the treatment options (including the option of no action) in a way that encourages objective evaluation of the risks and benefits while also minimizing cognitive biases (e.g., by using visual displays; Garcia-Retamero & Galesic, 2010), help patients determine which treatment option is most consistent with their personal goals and desires (i.e., values clarification and preference elicitation; Owens & Shekelle, 2013; M. Ryan & Farrar, 2000), and help patients communicate with their healthcare providers about how their preferences and values relate to the different options and to their overall healthcare goals (O'Connor et al., 2005). A recent Cochrane Collaboration Review showed that decision aids can improve both decision process (e.g., improved knowledge, expectations, and participation in decision making), and decision outcomes (e.g., reduced decisional conflict, and some evidence for increased value concordance) (Stacey et al., 2014).

However, having two criteria for defining a good decision (i.e., decision process and decision outcome) adds complexity to efforts to determine whether or not a single decision is good. One unanswered question is whether it is possible for a decision to be considered good if it was made via a good decision *process* (e.g., the patient had high knowledge of the treatment's risks and benefits), yet it also resulted in a poor decision *outcome* (e.g., the patient experienced high regret about the results of the treatment). A related question is whether a decision can be considered good if specific elements of a single criterion conflict; for example, if a patient does not receive value-concordant treatment (poor outcome), but does have high satisfaction and low regret (good outcome). There is little empirical guidance about how to evaluate the overall quality of such decisions. Another related issue is that patients' satisfaction with their selected decision option is likely to be conflated with its success, as suggested by research on decision outcome valence and counterfactual thinking,

which refers to the process of imagining alternatives to past events, usually in a direction that provides a better outcome than the one experienced (e.g., Hafner et al., 2016). For instance, a patient may have a good decision process (e.g., high knowledge of the treatment's risk and benefits) that led to a value-concordant decision to select an option that—as is often the case—was not without risks. Although those risks were known, and thus a complication would not necessarily have been unexpected, a poor clinical outcome is likely to reduce decision satisfaction and increase decision regret. In this case, was the decision a good one? It may be difficult to disentangle responses to negative clinical outcomes, although understanding whether and why an individual might still make the same decision in a given circumstance may be worthwhile.

## Decision Making Research: Measurement Issues

Determining whether or not a decision is good is further complicated by unresolved issues related to measurement. This complication expresses itself in three ways. First, although formative shared decision making work promotes measurement of both decision process and outcome criteria, the majority of shared decision making measures are outcome-related (Scholl et al., 2011). Additional development of measures of decision process constructs is needed (e.g., informed about options and outcomes, involvement in the decision). The second issue is how to measure specific constructs. For example, patient preferences are typically measured using patient-reported attitude scales, or by using values and preference elicitation methods such as utility elicitation, conjoint analysis, or analytic hierarchy processing (Liberatore & Nydick, 2008; O'Connor et al., 1998). However, there is evidence to suggest that different measurement methods elicit different patient preferences (e.g., Pignone, Brenner, et al., 2012). The third issue relates to the use of patient-reported versus observer measures, particularly for shared decision making. Measures of shared decision making typically assess the extent to which the patient is informed about key facts (i.e. knowledge), the decision is concordant with patient values (i.e., value concordance), and patients are a part of the decision making process to the degree they desire (i.e., participation). These constructs are predominately assessed with patient-reported measures, which may be subject to biases in recall or social desirability. Observer measures could help to address such limitations and provide a more comprehensive understanding of these constructs. Although some recently-developed observer measures exist (e.g., Observer OPTION; Elwyn et al., 2005), research in this area is vastly underdeveloped. Furthermore, even observer measures can be biased and/or have measurement error (Hoyt & Kerns, 1999).

Situated in the context of current scientific understanding of decision making and decision quality, stakeholders and audience members at the SBM and SMDM conference sessions agreed with the importance of both decision process and outcomes as criteria for a good decision. However, additional issues were identified as being central to answering the question, “what is a good decision?” These issues included interpersonal factors, structural constraints, affective influences, and values clarification methods. These issues are highly relevant to patients' experiences of both the process and outcomes of medical decision making; yet, each issue has gaps in scientific knowledge that limit the ability to develop a comprehensive definition of good decision making. We offer a brief overview of these topic areas and outline specific research questions that need to be pursued in order to ultimately

achieve clarity regarding what makes a good decision. This overview is not intended to be comprehensive, but rather a starting point from which to begin to examine these complex issues.

## Research Recommendations

### Interpersonal Factors

Although most commonly-used medical decision making theories focus primarily on the individual decision maker, stakeholders in both conference sessions noted the importance of recognizing that decision making unfolds in a social context populated by healthcare providers, a spouse or partner, family members, friends, and other people with similar health challenges. As a result, it is critical to consider the multiple ways that these diverse interpersonal relationships can shape the process and outcomes of a good medical decision, and how they can be affected by the process and outcomes of decision making.

Relationships between patients and their healthcare providers are pivotal in influencing medical decision making. Research on shared decision making and patient-provider communication has traditionally examined health decisions made in clinical settings, including decisions about medical screening, treatment, and lifestyle changes. Studies in this area have often been descriptive in nature, with a good decision considered to occur when patient-provider interactions cover information deemed critical to health decisions (e.g., Leyva et al., 2015; Nyrop et al., 2015) or display key communication features (e.g., the extent to which they demonstrate shared decision making; Boss et al., 2015). The interpersonal nature of health decision making is inherent to this line of research; yet, past work has not necessarily acknowledged the fact that compared to their healthcare providers, patients are often at a disadvantage when presented with a health decision because of the novelty, complexity, and stressfulness of the medical challenges they face. As one patient stakeholder explained, “the fundamental challenge that I see from the patient standpoint [is that] everybody else in the game gets to play it more than once... We [patients] have to live with the outcome or not live and it is that distinction between the one shot lived experience and the translation of information... derived from populations which is in some sense the hardest thing for any patient to make sense of.”

The multiple sources of imbalance between patients and providers in a given health decision context—imbalances in decision experience, power, influence, emotions—may ultimately interfere with patients’ ability to achieve a good decision process and/or outcome (Willems et al., 2005). Several stakeholders in the SBM session noted that provider-directed education focused on building communication and motivational interviewing skills may help to overcome these challenges (Berger & Villaume, 2013). One stakeholder also noted the importance of “the notion of empathy and how it can be factored into the decision support process.” Thus, research is needed to examine the role of empathy in decision making as well as methods for fostering empathy, as it may help providers to better understand and respond to the perspectives of patients and their families facing difficult medical decisions (Halpern, 2007; Larson & Yao, 2005; Loewenstein, 2005). Furthermore, the quality of the patient-provider relationship may serve as an important outcome to consider when determining whether or not a medical decision is good. As one physician observed, “It

would be easy for me to say, well, anytime when one of the parties feels like they acquiesced or gave up couldn't possibly be a good decision, but I think ... preserving the clinical relationship with a patient is actually bigger than any one decision, [and] there will be times where one party might feel like they're acquiescing on the decision or on the availability of something to preserve something greater." Thus, the quality of a given decision may need to be judged in the context of how that decision impacts the ongoing, fluid relationships between patients and their providers (McMullen, 2012; van Kleffens et al., 2004).

In addition, it is important to consider the roles played by people in a decision maker's social network, such as their family members and friends. On the one hand, people's beliefs about the values, expectations, and preferences of close others can influence the choices they make (e.g., Mahler et al., 2008), regardless of whether these beliefs are objectively true. These beliefs have been studied in research on subjective norms (i.e., beliefs about whether other people approve or disapprove of a given behavior; Ajzen, 1991; Ajzen & Fishbein, 1980), injunctive norms (i.e., beliefs about what people *should* do), and descriptive norms (i.e., beliefs about what most other people *actually* do; Cialdini et al., 1991). However, much is unknown about the source, nature, and effects of people's beliefs about what their close others want and need them to do in a medical decision making context.

Members of a patient's social network can also have direct influences on the decision making process, because patients often discuss important health decisions with a spouse or partner, family members, and/or friends (Ohlen et al., 2006; Schumm et al., 2010; Stiggelbout et al., 2007). Any influences stemming from these important relationships can have profound effects on the process and/or outcomes of health decision making given that decision makers spend a great deal of time with these individuals, value these relationships, and share goals and a future (Zhang & Siminoff, 2003). Indeed, evidence suggests that social network members can strongly influence people's decision making, both in terms of discrete health decisions (such as those involving medical treatments; Rini et al., 2011) and ongoing health decisions (such as those involving lifestyle changes and behaviors; Rempel & Rempel, 2004). Of course, the preferences, values, or informational needs of these different individuals may vary from the patient's and the healthcare provider's, and the presence of these individuals in a medical consultation can increase the complexity of the interaction (Laidsaar-Powell et al., 2013). It is unclear how the various perspectives of these individuals can or should be weighed in order to achieve a good decision making process and to reach a good decision outcome. As a decision scientist stakeholder noted, "each participant in the process adds new constraints about what is possible, but no one person defines the outcome of what is best. It's the combination of all of them that ultimately must determine what is right for one person in one situation."

Similarly, when evaluating whether a medical decision is good or not, it may be necessary to consider the effects of a given decision on patients' relationships with important people in their social networks. This issue was highlighted by stakeholders in the context of surrogate decision making (i.e., when an individual makes a decision on behalf of another person, such as a legal next of kin making decisions on behalf of a patient). As they explained, for some decision makers the experience "separates that person from the rest of the family [for] the rest of their lives." Being ostracized from one's family is not a good decision outcome, but



neither is making a decision that is at odds with one's knowledge and/or fundamental values. Hence, it is unclear how these various outcomes should be weighed in evaluating the quality of a decision, and research is needed to develop strategies for measuring these interpersonal outcomes.

Incorporating interpersonal factors into decision support interventions might improve the quality of the interventions and, consequently, facilitate good decision making processes and outcomes. This effort would require additional research to understand the various pre-existing features of relationships that promote or hinder good decision making processes and outcomes, and the various ways the decision making process may affect relationships that are important to decision makers' post-decision adjustment and quality of life in the future. Stakeholders in both sessions emphasized the importance of integrating effective sources of social support for medical decision making into clinical encounters. Research is needed to guide efforts to incorporate these support providers in a useful way. Such support could be provided by a partner, family member, friend, or peer. Patient navigators or lay health coaches—peers who are knowledgeable and experienced in a specific health context and can provide informational and emotional support—may be particularly useful (Braun et al., 2012; Freeman & Rodriguez, 2011). As a patient stakeholder observed, patient navigators can “relate to the patient and help the patient relate to the doctor who is giving them the information... The navigator role is one of support whereby they work with the patient from the time they walk in until the time that they no longer need that kind of support. So the whole issue of decision making takes on a whole different dimension because they are not making that decision by themselves and there is someone else that can help them.”

Similarly, one of the decision scientists posited that the process of decision support may be improved by “relying on other people who have gone through the experience and accessing their experience in such a way so that it can be shared either directly or indirectly with those folks who are facing the decision before they choose.” A small body of research confirms that stories about other people's experiences can influence health decision making (Denberg et al., 2006; Lacey et al., 2006; Shaffer et al., 2013). This kind of information may come from a variety of sources, including interactions with or observation of fellow patients (Meier et al., 2007), interpersonal communications with non-patients who describe others' experiences (DiFonzo et al., 2012; Ford & Kaphingst, 2009), and the media (Crist, 2005; Van Stee et al., 2012). Considerable psychological research has been devoted to exploring how narratives, social networks, and social comparison processes influence people's attitudes and behaviors (Allport & Postman, 1947; Aspinwall & Taylor, 1993; Burt, 1992; Contractor & Eisenberg, 1990; DiFonzo & Bordia, 2007; Festinger, 1954; Green & Brock, 2002; Monge & Contractor, 2003; van Laer et al., 2014), but relevant theoretical models have rarely been used to understand medical decision making.

In summary, interpersonal factors likely play a pivotal role in achieving both good medical decision making processes and outcomes. Discussion among the stakeholders identified several critical questions in need of additional research as the field strives for a comprehensive definition of good decision making. These questions, presented in Table 1, range from the descriptive, to the conceptual/theoretical, to the applied in nature.

## Structural Constraints

For the purposes of this paper, we define structural constraints as contextual factors that impinge on patients' abilities to make medical decisions (Gruskin et al., 2013). These constraints can occur at multiple levels of influence, including at the individual, interpersonal, organizational, community, and policy levels. We discuss two types of structural constraints: barriers to participating in the decision making process itself, and barriers to making quality decisions.

Much existing medical decision making research has focused on structural constraints that limit a patient's ability to engage in the decision making process (i.e., shared decision making). One of the critical elements of shared decision making is that an informed patient actively participates in the decision. Constraints to informed and shared decision making that have been well-studied include lack of access to adequate information about different treatment options and their potential benefits and harms, an imbalance in power between the physician and the patient, and clinical practice barriers (e.g., physician time constraints) (Joseph-Williams et al., 2014; Legare et al., 2008).

Several structural constraints specifically related to the "engaged patient" criterion were identified by stakeholders as needing additional investigation by researchers. The most prominent constraint was that many patients are unaware that they have a voice in making decisions about their medical care (Craddock Lee et al., 2015). It was also not clear which strategies are most effective for engaging patients who are uncertain about their role in the decision making process or who may be distracted by emotional or practical concerns in the process of shared decision making.

Although the shared decision making approach—the pinnacle of patient-centered care—depends on the involved patient, organizations and clinics should not attempt to force engagement on patients who genuinely wish to defer to clinician judgment. As one stakeholder described, "many people are dealing with so many other issues in their lives that they are coming to a doctor because they don't know what to do and they want to be taken care of... Their decision was to come to care or not come to care, [and] not [to] decide on a course of treatment." Although some research has investigated the extent to which patients do and do not want to participate in decision making (Chewning et al., 2012), little is known about the psychosocial consequences of attempting to activate patients who may not want to be involved. Indeed, it could be that well-meaning attempts to engage patients in the decision process when they do not want to be involved could inadvertently produce harm (Sheridan, Harris, Woolf, & the Shared Decision-Making Workgroup of the US Preventive Services Task Force, 2004).

Structural factors can also impede the ability of patients to achieve concordance between their values, preferences, and the actual treatment that is carried out (i.e., value concordance). There is wide variability in the extent to which patients receive value-concordant treatment (Winn et al., 2015). Several factors contribute to a lack of value concordance, including payment structures that reward higher healthcare utilization, poor infrastructure, and fragmentation of care (Ellis, 2000; Lara et al., 2001; Legare & Witteman, 2013). Fragmentation of care was also identified during the conference sessions as limiting

which information is presented to patients (e.g., a surgeon might not mention non-surgical options that would be the purview of a different specialty provider, despite the fact that such options may be relevant to the patient).

Research is needed to identify and more effectively manage processes associated with fragmentation of care that inhibit the provision of alternative decision options (Stange, 2009). Better understanding of the healthcare provider perspective is also needed, as it may illuminate how, why, and under what circumstances providers are more or less likely to have patients who receive value-concordant care. Qualitative methods could be especially useful for addressing these research questions (Drew & Schoenberg, 2011; Hay & Craddock Lee, 2009). Another issue mentioned during both sessions is that population/public health recommendations, such as those related to the age for ceasing cancer screening, might not be appropriate for every individual. Research aimed at exploring opinions about this issue at the patient, provider, and system levels is needed.

Some structural factors influence patient decisions by restricting the extent to which a particular treatment option is available in real, practical terms. These factors are described in the published literature and were discussed extensively by stakeholders and audience members at both conference sessions. Specifically, patients who do not have access to reliable transportation, sufficient healthcare coverage, paid leave from work, and alternative childcare or eldercare services may not be able to choose a desired option because doing so is either logistically infeasible or has such severe negative consequences for other aspects of their lives that the choice is practically infeasible (Hunleth et al., 2016; Lara et al., 2001). One stakeholder reported that rural patients facing a diagnosis of ductal carcinoma in situ of the breast may choose mastectomy over lumpectomy plus radiation in part because it was not possible to make multiple trips to the treatment center located three hours away: “If three quarters of your patients do not have paid time off, then the choices they are making are not your clinical outcome choices. The choices are, ‘which of the options I can do and still get back to my life and not lose my job’.” Choosing mastectomy for ductal carcinoma in situ of the breast may not appear to be a good decision from the perspective of a healthcare provider or of clinical outcomes research. Yet, this decision is responsive to the patients’ intransigent structural constraints, which highlights an additional perspective that needs to be considered in evaluations of decision quality.

The need to finish treatment so that life could resume normality was mentioned several times in both conference sessions by multiple stakeholders. Research is needed to better explicate what it means to patients to return to “normal” and how to facilitate treatment decisions in a way that accommodates this need. A related question is whether it is possible to say that a good decision has been made, if it was made only because it was the treatment that placed the least logistical burden on the patient.

Some decision aids and patient education materials have been criticized for emphasizing individual decision making and responsibility while also overlooking structural factors that can constrain patients’ decisions (Hunleth et al., 2016). Providing information without considering structural constraints can cause emotional distress, as recounted by one stakeholder: “a patient who...[became aware] of treatment options that were not actually

viable, practical options for her [due to structural constraints] explicitly said, ‘I wish you had not told me this. I would be a happier person than I am now’... We need to pause and reflect upon the effects of our informational introductions.” However, another similarly situated patient might want to know all the options, and might consider methods of obtaining sufficient resources to make a particular option viable. These various critiques lead to an important series of research questions concerning structural constraints that are presented in Table 2, and can be used to guide future research.

### Affective Influences

The role of affect in decision making is complex. Under certain circumstances affect can interfere with the process of making a medical decision. For example, fear can impair comprehension of information provided by providers, which impedes patients’ ability to become knowledgeable about their treatment choices (van Osch et al., 2014). As illustrated by a patient stakeholder in one of the conference sessions, “the room goes dark, things get quiet, and you say ‘what did you say?’ And they repeat. And eventually you bring yourself to some realization and understanding of what they said because the first thing that comes to your mind is that you are going to die.” However, affect also provides valuable guidance to a decision maker by helping them understand what is important to them, informing the perception of the risks and benefits of each choice, and facilitating the evaluation of disparate treatment outcomes (Peters et al., 2006; Pham, 2007; Slovic et al., 2005). This section examines two types of affective influences on medical decisions and on decision quality: as something that is experienced in the moment (i.e., “anticipatory” emotions) and as something that one imagines might be experienced in the future (i.e., “anticipated” emotions) (Loewenstein et al., 2001).

Ample research demonstrates that different anticipatory affective states (e.g., fear, anger, happiness, sadness, disgust) influence decisions differently (Lerner et al., 2015). However, the specific relationship between affect and decision making depends on a combination of patient factors and characteristics of the decision itself (Consedine et al., 2004). For example, one can have affective feelings toward a disease (e.g., fear), towards treatment options (e.g., fear, hope), and towards different aspects of treatment options (e.g., positive affect towards benefits, negative affect towards risks), and each of these considerations can have different effects on decisions. Whereas one person might *forego* screening due to fear of finding out she has cancer, another might *undergo* screening because he fears late detection (Consedine et al., 2004; Hunleth et al., 2016). Fear and concern can also prompt people to make decisions resulting in under-treatment of disease due to concern about experiencing side effects (Horne et al., 2007). Alternatively, patients may knowingly choose highly intensive treatments to maintain hope for the future (Agrawal et al., 2006), or to avoid, in one stakeholder’s words, worrying “about the future prospect of a risk... continually, for the next few years.” Such decisions seem ideally suited to be facilitated via decision support tools, but interventions that incorporate examination of anticipatory affective states either preceding or following use of decision aids are very sparse (Stacey et al., 2014).

People not only directly experience affective states in the moment, but they also anticipate how they might feel in the future. For example, healthy people often overestimate how much an illness or disability will negatively impact their lives (Halpern & Arnold, 2008; Ubel et al., 2005). Stakeholders in both conference sessions highlighted such *affective forecasting errors* as potential barriers to good decision making that need to be addressed. For instance, one decision scientist asked, “people do adapt and they do move forward...How do we give people some insight into that [process]?” Evidence suggests that narratives may be one tool that can reduce affective forecasting errors related to colorectal cancer screening (Dillard et al., 2010). Adapting and testing narrative interventions among other medical decision contexts is an incremental step to evolving this line of research. More research is needed to develop interventions that improve affective forecasting and to incorporate such interventions into decision support tools (Elwyn et al., 2010).

People also anticipate the extent to which they might feel regret in the future if a negative outcome were to occur (Loewenstein et al., 2001). In general, people who anticipate regretting a decision if it were to result in a negative outcome are more likely to engage in health protective behavior (Sandberg & Conner, 2008). However, unlike process regret (i.e., feeling regret about how a decision was made) and outcome regret (i.e., feeling regret about a bad outcome that occurred) (Connolly & Reb, 2005), anticipated regret has been relatively understudied in the context of clinical medical decision making and decision support. Most medical decision making research that examines anticipated regret treats it as a predictor of patient decision making separate from typical decision quality metrics such as decisional conflict (Hersch et al., 2014; van Dam et al., 2013). Although decisions made on the basis of anticipated regret can be considered good if a patient has an accurate conceptualization of how she would feel, anticipated regret is also subject to affective forecasting errors. Thus, if a patient bases a decision on anticipated regret but she inaccurately predicted how she would actually feel, the decision could be considered flawed. Research should examine the extent to which patients’ anticipated regret is and is not subject to affective forecasting errors, and the conditions under which such inaccurate predictions are most and least likely to occur. Research could also examine the extent to which anticipated regret might lead patients to ask for someone else to make the decision so that they will not “blame themselves” if there is a poor clinical outcome.

It is also important to highlight that stakeholders in both conference sessions noted that providers not only feel anticipated regret about their patients’ potential negative health outcomes, but also outcome regret when their patients experience negative outcomes. Furthermore, both types of regret may influence providers’ treatment decisions and recommendations. However, provider regret and its implication for good decision making is severely understudied in the medical decision making literature (Feinstein, 1985; Mamede & Schmidt, 2014).

This collection of research findings and stakeholder input leads to several unanswered questions about affective states, their relationship to the process of medical decision making, and what it means to make a good medical decision (see Table 3). Improving understanding of these questions will help clarify the function of affect throughout the decision making process and, consequently, inform the development of conceptual models of good decision

making and improve the utility of decision aids and other decision support tools (Elwyn et al., 2011).

### Values Clarification Methods

Stakeholders in both sessions described a need for improved, evidence-based methods for eliciting and clarifying patient values and preferences both within and outside of medical consultations (Bridges, 2003; M. Ryan et al., 2001). Values clarification methods (VCMs) are “methods to help patients think about the desirability of options or attributes of options within a specific decision context, in order to identify which option he/she prefers” (Pignone, Fagerlin, et al., 2012). VCMs are grounded in social psychology and have a rich history in a variety of fields, including conflict resolution, economic utility theory, and decision process theories (Kinnier, 1995). VCMs are grounded in economic utility theory and decision process theories and have been used increasingly in healthcare settings, and most often address treatment decisions (Witteman et al., 2016). VCMs include (but are not limited to) rating and ranking, balance sheets, as well as conjoint analysis and discrete choice experiments that utilize series of hypothetical choices to estimate values of options and outcomes (M. Ryan & Farrar, 2000; M. Ryan & Gerard, 2003). VCMs can take many forms, but are most often designed to be completed on paper, and in decision aids are presented after the information sections (Witteman et al., 2016).

Recent reviews (Fagerlin et al., 2013; Witteman et al., 2016) have pointed out that to date, VCMs lack systematic theoretical grounding, and as a result it is often not clear how to best achieve the objectives of VCMs, or even how to identify what the objectives of VCMs should be. For example, few methods explicitly present decision trade-offs, provide the opportunity for iterative decision making, or show how options align with different values, which may (or may not) be important for achieving value-concordant decisions (Witteman et al., 2016). Moreover, it is often assumed that taking more time to think carefully about a decision is inherently beneficial (de Vries et al., 2013), but this may improve feelings about the decision rather than the decision itself (Scherer et al., 2015).

Stakeholders in the sessions emphasized the importance of identifying ways that patients and providers can more effectively communicate with each other during consultations about patient values and preferences that are relevant to the medical decision (Elwyn et al., 2013; Siminoff et al., 2012; Zhang et al., 2010). Stakeholders also discussed several of the challenges facing patient preference elicitation research and VCMs. As one decision scientist pointed out, a central challenge is the fact that patients typically have not thought about their preferences in serious medical contexts because they have rarely “been down this road before.” As one patient representative explained, “I mean we talk about values but let’s be honest. Most patients don’t walk around saying ‘I’m a person who has this value.’ We construct this stuff in the moment when you ask us and we don’t have anything – yes, there are some innate things that we value but it doesn’t look like what we get when [decision support efforts] elicit values.” Because preferences and values are often constructed in the moment, they may change over time, or change depending on how they are elicited (e.g., rating and ranking vs. conjoint analysis; Pignone, Brenner, et al., 2012). Thus, a patient who appears to be making a value-concordant treatment decision at one moment in time or

following a particular elicitation method may appear to be making a value-discordant decision when her values and preferences are elicited at a different time or in a different manner. Research is needed to evaluate the extent to which values and preferences are malleable, and how this malleability influences whether and how value concordance can be used to identify good decisions.

Additional challenges can arise when patients have multiple, conflicting preferences. For example, a patient considering treatments for early-stage prostate cancer may have both a strong preference to avoid impotence, and a competing strong preference to get the prostate cancer out of his body. Given that surgical intervention can cause impotence, such a situation requires a difficult trade-off, is characterized by high uncertainty, and the patient's ranking of these preferences may change frequently and be influenced by minor differences in elicitation method. Moreover, it may be the case that these conflicting preferences can never be resolved satisfactorily. It is unclear how to best support decision makers in such cases, or what the goal of VCMs should be when these cases arise. For instance, the goal could be to help the patient arrive at a stable preference structure. Alternatively, the goal could be to simply encourage a decision process that allows the patient to achieve a conventionally good decision outcome (e.g., to feel satisfied about the decision, to minimize regret) (Scherer et al., 2015).

Stakeholders also acknowledged that any development of innovative, theory-based VCMs needs to be tempered by the reality of actual patient decision making. As noted by a patient representative, "I can assure you that patients with breast cancer don't move in this kind of definitive consideration as far as whether or not you made the best decision...some patients, all they want is to have it removed, let me go through the treatment I have to go through and get on with my life. All the other kinds of things that can seem so esoteric don't mean a darn thing to me." As exemplified by this perspective, current theoretical models of decision making and traditional VCMs may need to be expanded or revised to incorporate the various factors about which patients have preferences. For instance, VCMs often focus primarily on the risks and possible outcomes of treatment, yet focus less on the process of treatment (e.g., how to get treatment, when and whether treatment will end), which may be of great importance to a patient. Hence, measuring value concordance—and by extension, whether a decision is good—needs to evolve to allow patients to incorporate the specific factors that they have preferences about, rather than focusing exclusively on the factors that experts believe patients *ought* to have preferences about.

Stakeholders further emphasized the need for cultural competence. As the medical anthropologist noted, patients' personal realities are embedded within larger social and structural contexts (Hoerger et al., 2013). For this reason, the universalizing "one-size fits all" approach to value and preference elicitation is likely to be suboptimal. In contrast, recognizing cultural differences between groups argues for adapting certain components of interpersonal communication algorithms and asynchronous measurement tools (typically developed in Western, upper-middle class environments) to the lives of other groups, whose unique life experiences contribute to different decision making processes and affective responses (P. B. Smith et al., 2006; Williams et al., 2008). Using a breast cancer treatment decision aid designed for Asian American women as an example, narratives may achieve

higher levels of value concordance when references to alternative choice costs and benefits are embedded in socially and structurally relevant contexts of families, friends, and work. At the same time, it is clear that variation occurs within groups on targeting dimensions such as cultural values and social norms (Oyserman et al., 2009). For this reason, it is important to develop VCMs that are sensitive and responsive to individual differences within cultural groups (Alden et al., 2014).

Moreover, current VCMs are limited in scope. As noted previously, they do not typically address variations in patient preferences over time, and also do not address the possibility that preferences and values may change in response to a medical course or a life event. As one physician pointed out, “we need follow up and close communication as we go forward because your values might change, the science may change, your ability to adhere to this might change or we may not be getting the outcome that we thought was important.” In the case of ongoing medical treatment, a decision that was once value-concordant may become discordant as values change with time, experience, and life events. VCMs, and decision aids more generally, also do not capture the temporal order of events that occur during the decision making process. VCMs are usually limited to assessing preferences for the overarching single decision (e.g., breast cancer treatment). Yet, patients make a series of decisions in more of a sequential and interrelated fashion: Will I have surgery or only chemotherapy? If chemotherapy, will I have my treatment at the local hospital or the breast cancer clinic two hours away? If the breast cancer clinic, will I drive or take a bus or ask my sister to take me? Each of the ‘follow-up’ decisions is influenced by the patient’s personal values and preferences (as well as structural constraints), and methods are needed that reflect this reality.

In summary, insights from both sessions emphasized the importance of eliciting patient values and preferences, but also identified a number of complexities in how this is achieved and how a decision is ultimately judged as value- or preference-concordant. Guided by stakeholder input from our sessions and gaps in the current literature, we propose several questions for further study, as presented in Table 4.

## Conclusions

The field of medical decision making continues to strive toward achieving greater clarity about what it means to make a good medical decision. The traditional criteria, encompassing both the processes and outcomes of decision making, are necessary components for defining the quality of a medical decision. However, insights from multiple stakeholders reflecting a range of relevant disciplines and perspectives have highlighted the complexities inherent to achieving this goal. The major lesson learned from these sessions was that the traditional decision quality criteria and theoretical approaches alone are not sufficient to fully capture people’s lived decision experiences, and that a “one size fits all” approach to theories of decision making and definitions of what constitutes a good decision may not be appropriate.

Support for a more tailored approach to defining a good decision comes directly from the stakeholders, who emphasized that, although decision processes and outcomes are important, several other considerations complicated the decision process. For example, the



decisions patients make are constrained by social and contextual factors that can shift patients' priorities and preferences and complicate their decision making by introducing more salient issues than clinical effectiveness or other medical outcomes. Similarly, affect has powerful effects on the ways that individuals approach and make medical decisions. Finally, although patient values and preferences are important aspects of decision making, they are malleable and heterogeneous. Existing values clarification and elicitation methods are not sensitive to these realities of patient medical decision making. Unfortunately, current theoretical frameworks that guide medical decision making research do not sufficiently address these critical considerations. Research that explores these considerations, identifies the effects of these considerations on medical decisions, and integrates the results into theoretical models would advance the science of medical decision making and enhance interventions that aim to improve patient decision making.

Another reason one singular definition of a "good" decision may be insufficient stems from gaps in existing theoretical frameworks. Growing research suggests that the actual decision process is much more complex and dynamic than is indicated by many theoretical frameworks, which provide a static snapshot of a changing situation. For example, rather than a singular event, a decision may occur in phases over time (Beryl et al., 2016). Decision resolve (i.e., "firm determination" to maintain a decision, Beryl et al., 2016) also varies over time and plays a key role in whether or not a patient undergoes therapy. These complexities are not represented in current theoretical frameworks. These frameworks are also silent on whether decisions may involve feedback loops or interactions among key variables. It is also unclear whether people who make a greater number of challenging decisions learn how to navigate them more easily and in a way that is more consistent with their preferences. Medical decision making researchers might benefit from collaborations with scientists who examine complex multi-level phenomena (e.g., physical activity) from a socio-ecological perspective (Stokols, 1996).

In order to develop a comprehensive definition of decision quality and to advance the theory and practice of medical decision making, it is critical to consider novel factors that not only shape the process by which patients make medical decisions and the outcomes of those decisions, but also those factors that could serve as new metrics for identifying a good decision. This requires an acknowledgement and better scientific understanding of the real ways that patients make decisions. Further research is needed to fully understand how each of the issues raised in this article—interpersonal factors, structural constraints, affective influences, and values clarification methods—contributes to the definition (or multiple definitions) of good medical decision making. To truly comprehend these factors, it is critical to include the voices of the medically underserved in this research, including those who may be underserved due to race, ethnicity, income, education, literacy, geographic residence, language barriers, immigrant status, and acculturation. Community engaged research should be a key methodological strategy for achieving this goal (McCloskey et al., 2011; Minkler & Wallerstein, 2008). Such research will expand the way in which researchers and providers ultimately define a good medical decision, and consequently will improve the ability to measure and intervene upon the decision making experience.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**

Suggested questions to guide research on the role of interpersonal processes in “good” medical decisions

Descriptive Questions	Theoretical/Conceptual Questions	Applied Questions
<ul style="list-style-type: none"> <li>- In what situations and in what ways do interpersonal influences change patient decision making? Are these influences beneficial or detrimental to decision processes (e.g., obtaining knowledge) and outcomes (e.g., regret)?</li> <li>- Which strategies are best for helping providers partner with patients when their respective cognitive and emotional reactions to the decision are highly disparate (e.g., when the decision is perceived as familiar or routine by the provider but is perceived as novel and overwhelming by the patient)?</li> <li>- When during the decision making process will support offered by various individuals be effective versus ineffective?</li> </ul>	<ul style="list-style-type: none"> <li>- What does a good decision look like when a patient’s preferences contradict her/his provider’s preferences and/or the preferences of other social network members?</li> <li>- How does incorporating the social and interpersonal nature of decision making change the definition of a good decision making process?</li> <li>- When multiple decision makers are involved, should a good decision be defined by achieving a good decision for one person (e.g., the patient), a satisfactory decision for as many people as possible, or some other balance?</li> <li>- Do current theoretical models of decision making apply to surrogate decision makers (i.e., those making decisions for others)?</li> </ul>	<ul style="list-style-type: none"> <li>- What sources of decision and social support are most effective for helping patients and their families make good medical decisions?</li> <li>- Which healthcare providers should deliver sources of decision and social support (e.g., medical family therapists, social workers, clinicians, patient navigators) and how can they be appropriately reimbursed?</li> <li>- How do we effectively integrate sources of decision and social support into complex decision contexts (e.g., high-stakes decisions; decisions with time constraints; individuals with difficult family dynamics involving poor communication, estrangement, geographic distance, etc.)?</li> </ul>

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**Table 2**

Suggested questions to guide research on the role of structural constraints in “good” medical decisions

Descriptive Questions	Theoretical/Conceptual Questions	Applied Questions
<p>- How often, for which patient populations, and for which treatments are decisions made primarily because structural constraints dominate the decision process?</p> <p>- How do current decision quality metrics (e.g., treatment satisfaction, decision regret) and clinical outcomes (e.g., morbidity, mortality, quality of life) differ between patients whose decisions are and are not constrained by structural factors?</p> <p>- What are the psychosocial consequences of introducing patients to an array of treatment options that may not be viable for them due to structural constraints? Relatedly, to what extent, if any, do decision support interventions “alienate” and/or “contribute to [patients’ feelings of] blame, guilt, or shame” for decisions that result in poor outcomes (Hunleth et al., 2016)?</p>	<p>- Can a decision be considered good if it is made solely on the basis of a structural constraint (e.g., lack of paid time off work is the dominant factor in a patient’s decision to undergo Treatment A instead of Treatment B)?</p> <p>- How should consideration of structural constraints be incorporated into the decision making process and decision support tools—as a type of patient preference, or as a barrier to treatment that can be overcome? Furthermore, how can structural constraints be incorporated into patient decision making in ways that acknowledge their importance, but avoid perpetuating health inequities?</p> <p>- How do decisions change when structural constraints are removed, and what implications does this have for defining a good decision?</p> <p>- From a bioethics perspective, when, if ever, is it appropriate for a provider to not disclose a treatment option because the provider knows that the option is not feasible for the patient?</p>	<p>- Can collaborative teams comprised of social workers, decision psychologists, experts in preference and values elicitation, and others develop concrete strategies and programs that help patients overcome situational factors that might constrain their decisions to options that are feasible, rather than preferred?</p> <p>- How do state and/or nationwide policies that reduce or eliminate common structural constraints to decision making affect health economic outcomes (e.g., effects on quality-adjusted life years, QALYs; disability-adjusted life years, DALYs)?</p> <p>- What are the implications of provider and healthcare system performance incentives and penalties, which are intended to influence both healthcare costs and outcomes, for the process and outcomes of patients’ medical decisions?</p>

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**Table 3**

Suggested questions to guide research on the role of affective influences in “good” medical decisions

Descriptive Questions	Theoretical/Conceptual Questions	Applied Questions
<ul style="list-style-type: none"> <li>- How, why, and under what conditions do patients make affective forecasting errors when making medical decisions, and what are the consequences in terms of their decision satisfaction and what it means to make a good decision?</li> <li>- To what extent and under what conditions is anticipated regret subject to affective forecasting errors?</li> <li>- How do instructions for evaluating decision choices that emphasize a focus on feelings versus focus on details affect the choices made?</li> <li>- How does affect change throughout the decision making process, following use of decision aids, through the various parts of the treatment process (e.g., prior to, during, and after each radiation therapy session), and after the treatment process (i.e., after all decisions have been made)?</li> <li>- How does a healthcare provider’s anticipated regret influence treatment recommendations and decision support strategies, and what are the implications for what it means for a patient to make a good decision?</li> </ul>	<ul style="list-style-type: none"> <li>- When, if ever, can a decision be considered good when it is made because a patient prioritizes affective considerations (e.g., hope, fear) over empirical medical evidence?</li> <li>- Some decisions generate multiple affective states, some of which may conflict (e.g., a treatment that offers hope for extended survival but also frightening side effects). How do patients integrate the experience of these disparate affective states to arrive at a decision, and under what criteria should such a decision be considered good?</li> <li>- What is the role of ideal affect in patient decision-making?</li> <li>- What is the relationship between anticipated regret and good decision making? Is it possible to identify situations when it is and is not appropriate for patients to base their decisions on anticipated regret?</li> <li>- How should the use of affect be incorporated into the definition of a good decision outcome? Should high treatment satisfaction and low regret be supplemented by other affective states? If so, which affective states?</li> </ul>	<ul style="list-style-type: none"> <li>- How can patient decision support tools incorporate the concept of affective forecasting errors and their potential biasing influence on decisions? Furthermore, under what circumstances, if any, should decision support tools be designed to overcome the influence of affective forecasting errors on decisions?</li> <li>- How might decision support tools include consideration of patients’ changing anticipatory affective states throughout the decision making process?</li> <li>- How can we develop an array of decision support tools that facilitate good decision making for groups of individuals who may experience affective states differently and at different points in the decision process? Such work would likely require formative research to characterize patients’ affective experiences at different points in the decision making process.</li> <li>- How can decision researchers help patients harness fear and other emotions to make good decisions? What strategies can be used to resolve fear when it is likely to impair decision making and utilize fear appropriately when it can improve decision making?</li> </ul>

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**Table 4**

Suggested questions to guide research on the role of values clarification methods (VCMs) in “good” medical decisions

Descriptive Questions	Theoretical/Conceptual Questions	Applied Questions
<ul style="list-style-type: none"> <li>- To what extent, and under what circumstances, are patient preferences malleable over time, context, and elicitation method?</li> <li>- Are the values and preferences that are included in VCMs the same values and preferences that patients of different backgrounds care about?</li> </ul>	<ul style="list-style-type: none"> <li>- How does the malleability of patient preferences influence our ability to draw inferences about the quality of a decision based on value concordance?</li> <li>- How can we incorporate the idea of values changing over time and experience in VCMs? Should VCMs include longitudinal follow-up to allow measurement of more distal outcomes?</li> </ul>	<ul style="list-style-type: none"> <li>- How can we approach the design of VCMs in a way that ensures that the values and preferences that patients of different backgrounds care about are adequately reflected?</li> <li>- Can we develop VCMs that better address the fact that most medical decisions are not a single, discrete choice, but rather reflect a sequential paradigm?</li> <li>- In what ways might VCMs encourage patients to consider the downstream consequences of a discrete decision?</li> </ul>