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Aiding end-of-life medical decision-making: A Cardinal Issue Perspective

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Many challenges exist in bridging communication gaps between clinicians and patients in end-of-life decision-making in which there is a continuum of treatment possibilities (Breen et al., 2001; Pochard et al., 2005; White et al., 2007). The shared decision-making approach has demonstrated the potential for improving decisions to achieve better quality of care (Teno et al., 2004; Thompson et al., 2004; Dowling and Wang, 2005; Makoul and Clayman, 2006). However, sharing of end-of-life decisions in practice happens infrequently due to factors such as time constraints, inadequate communication, clinical situations (e.g., sensitive topics, including end-of-life discussions), and patient characteristics (e.g., older age and poor health condition; White et al., 2007; Joseph-Williams et al., 2014). Additionally, debate regarding exactly what shared decision-making entails and how it can and should be adopted into practice has likely also hindered its acceptance by medical providers (Makoul and Clayman, 2006). We propose a new approach — using the Cardinal Issue Perspective on decisionmaking as a checklist for routinely performing shared decision-making in end-of-life situations. The Cardinal Issue Perspective has the potential to streamline and address important decision-making considerations that may not be fully attended to in current clinical shared decision-making models and practice.

The Cardinal Issue Perspective (Yates, 2003), based on the existing extensive literature in decision science, is a comprehensive and well-recognized framework for managing decision processes and ensuring quality. Its utility has been demonstrated in a variety of practical settings, including understanding the decision-making of elderly people in value-laden healthcare decisions (Bynum et al., 2014). It theorizes that a decision process must address all 10 cardinal issues in some way, e.g., by deliberation, habit, or social norm. The more adequate the resolutions are, the more likely it is that the decision at hand will be successful. A lack of awareness or poor understanding of all 10 cardinal issues by decision makers, however, may result in problematic resolutions. For instance, a patient or a surrogate decision maker who is unaware of palliative medicine options and long-term implications of life-sustaining treatments may later find that the decision is in conflict with personal values and the outcomes not as expected (Teno et al., 2000; Nelson et al., 2005). Therefore, we suggest using the 10 cardinal issues checklist (Yates, 2003) for clinicians, patients, and surrogate decision makers to scrutinize decision-making at each phase to smooth the communication process and maximize the chance of making an effective decision (Table 1 for an end-of-life decision example). Current models (e.g., Makoul and Clayman, 2006) may not fully address all of the cardinal issues, suggesting opportunities to improve shared decision-making.

The first three *cardinal issues* are devoted to setting the stage for decision-making efforts. *Need* emphasizes bringing up the decision problem at the right time and discussing the urgency of the decision, giving clinicians, patients, and surrogate decision makers opportunities to discuss the benefits and risks of watchful waiting vs. actively making a decision, e.g., continuing current treatments and withdrawing life support. In addition to determining decision makers and their preferred level of involvement, *Mode* encourages not only providing resources to support decision-making (e.g., consultants, decision guide worksheets, and websites) but also discussing the content together to help patients and surrogate decision makers understand issues pertinent to decision-making. *Investment* refers to kinds and amounts of resources stakeholders contribute in the decision-making process itself. It is not often discussed in shared decision-making models. Quantifying the resources, such as material (time and money) and emotional efforts (stress and pressure), that decision makers can afford to invest in making a decision, will help them manage the decision process and balance other aspects of life. Excessive devotion of resources may result in decision-making burnout and potentially undermine decision makers' well-being.

The next five *cardinal issues* are regularly reflected in shared decision-making models (Makoul and Clayman, 2006). In current practice, *Options* (reasonable options), *Possibilities*

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Table 1. Cardinal issues checklist: illustrative end-of-life shared decision-making

Cardinal issue	Key question for discussion ^a	Key points to address
1. Need	Why are we (not) thinking about end-of-life decisions at all? Should an end-of-life decision even be considered?	Before entering the decision-making process, articulate and discuss the time frame for the decision, so that clinicians, patients, and surrogate decision makers can plan accordingly and will not decide too early or late.
2. Mode	Who will make the end-of-life decision? What resources and tools will they use to approach this decision?	As patients and surrogate decision makers may value different information and support, it may be helpful for clinicians to provide them with a list of credible resources (e.g., people they can talk to and medical factual information), show them how to use these resources, and discuss the information and process together.
3. Investment	What kinds and amounts of resources will be invested in making the end-of-life decision?	Acknowledge and bring to light that the decision-making process itself is costly. Being aware of investment during the decision-making process will help decision makers manage decision burden.
4. Options	What are the reasonable options for dealing with the patient's current situation?	As there could be a variety of options (e.g., home hospice care, comfort care in the hospital, hospice along with life-prolonging care), it is important that clinicians openly discuss reasonable available options with patients or surrogate decision makers.
5. Possibilities	What important outcomes could occur if a certain option were implemented?	We suggest tailoring conversations to individual needs and prioritizing discussing "important" outcomes that are central to patients' and their families' everyday life — information that is actually pertinent to decision-making, in addition to medical facts.
6. Judgment	What is the probability that each important possibility would actually happen?	Probabilities should be based on evidence (if up-to-date and available) and/or clinicians' best judgment (if best evidence unavailable) and discussed in an understandable manner. It is not sufficient that clinicians just convey uncertainty or show decision makers numbers without interpretation.
7. Value	How much would the patient and surrogate decision makers care about an outcome if it were realized?	Value clarification methods can be used to elicit patients' and surrogate decision makers' values pertinent to the decision problem at hand. Forecasting future emotions about each important potential outcome, such as regret, is important.
8. Tradeoffs	How could the decision maker evaluate the relative pros and cons of the options to determine the overall suitability of each option?	Tools need to be provided to guide decision makers on the process of resolving tradeoffs. Consider compensatory strategies or noncompensatory strategies, both of which require an understanding of patients' and surrogate decision makers' values pertinent to the decision problem and sacred values, if any.
9. Acceptability	A tentative end-of-life decision is made. Will other people object to this decision and how to address their concerns?	Opinions of other people, including stakeholders or those who are not participating actively in the decision but might be affected by it, should be considered.
10. Implementation	How can the tentative decision be implemented and sustained?	Integrate long-term preparation and planning for the decision's consequences at an earlier stage in the process.

^aAdapted from content in Yates (2003).

(potential outcomes of each option), and Judgment (probabilities that the outcomes might occur) are emphasized, whereas Value (likes and dislikes about the outcomes) and Tradeoffs (weighing benefits and risks) are not yet implemented well. When discussing the benefits and risks of end-of-life care options, we suggest that the information should not only include what clinicians consider important based on medical evidence but also what patients and surrogate decision makers view as pertinent to address the things they care about the most. For example, a clinician may focus on technical pros and cons of a treatment and immediate outcomes, but fail to discuss long-term implications for the patient and family, leading to potentially unanticipated financial and emotional issues in the future (Nelson et al., 2007; McCormick et al., 2015). Clinicians often find it hard to discuss Value, even though patients and families find discussing values and spiritual beliefs important for end-of-life care quality (Steinhauser et al., 2000). To further understand what best serves patients, we note the importance of using value clarification methods to explore patients' and surrogate decision makers' values that may directly

influence the decision (e.g., religious beliefs) and forecasting feelings regarding potential outcomes accurately to reduce postdecisional regret. In addition, clinicians and decision makers may sometimes think that an understanding of information and values will automatically lead to a decision, so it is important to provide specific guidance to resolve Tradeoffs among options how the pros and cons of each option should be weighed against each other in order to make a decision. Value clarification methods, including using compensatory and noncompensatory strategies, could facilitate Tradeoffs discussions and resolution. Compensatory strategies allow pros to compensate for cons, e.g., multiattribute utility theory. Noncompensatory strategies exclude any option with an unacceptable downside even if it yields tremendous benefits, which further suggests a need for understanding patients' and surrogate decision makers' ranking of relevant values, sacred values in particular, for the decision problem (Yates, 2003; Fagerlin et al., 2013).

Two issues concern the making of the final decision. *Acceptability* not only involves a mutual agreement between

clinicians, patients, and surrogate decision makers but also deals with potential objections from other participants in the decision event. *Implementation* addresses the practical ways to carry out and sustain the treatment or post-procedure care, which is not often the focus in shared decision-making (Makoul and Clayman, 2006). We recommend reviewing the 10 *cardinal issues* again after a tentative decision has been made, particularly if there are problems dealing with *Acceptability* and *Implementation*.

The goal of shared decision-making and the use of decision aids are to achieve high-quality decisions. However, what "high-quality" means and how to appraise or measure decision quality is somewhat obscure. A high-quality decision has been proposed to be one that is "informed, consistent with personal values, and acted upon" (O'Connor, 1995). In end-of-life medical decisions, there are numerous abstract and complex contributors to decision quality, necessitating a more comprehensive definition to evaluate decision-making in these contexts.

We suggest decision quality entails evaluation of both decision outcome and process. Decision outcome criteria include four dimensions: aims, needs, aggregated outcomes, and rival options. An effective shared decision should ideally meet the goals of clinicians, patients, and surrogate decision makers, satisfy the needs of the intended beneficiaries (patients), yield outcomes (for patients) that are at least as satisfying as those yielded by other alternatives, and result in minimal decisional conflict and regret. Decision process criteria include five dimensions: time, money, disagreements among decision makers, emotional burden, and knowledge. An effective decision should consume manageable material and emotional costs and inform decision makers about the current decision to be made, while preparing them for the future. We note that efforts to reduce process costs should not jeopardize decision outcomes, as the decision makers may likely modify their decisions, which inevitably increases process costs (Yates, 2003).

A strength of our decision quality definition is that it emphasizes personal considerations and values (e.g., the aims, goals, regret, emotions, and perceived importance of various costs), along with objective measures (e.g., aggregated outcomes and material costs), as an effective decision should satisfy the interests and values of intended beneficiaries (Yates, 2003). Many shared decision-making interactions focus on explaining benefits and risks without fully incorporating patients' and family's values (Fried, 2016). We believe that values are not only preferences or beliefs about different options but also guiding principles that will influence the ultimate decision and its quality. The 10 cardinal issues together contribute to every determinant of decision quality and may hold the potential to promote better quality decision-making than current models, although more research is warranted to demonstrate its utility in actual shared decisionmaking settings. When implementing shared decision-making for end-of-life decisions, clinicians can discuss important questions and provide resources as suggested by the 10 cardinal issues checklist.

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