

Value Awareness: A New Goal for End-of-life Decision Making

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Abstract

The principal policy tool for respecting the preferences of patients facing serious illnesses that can prompt decisions regarding end-of-life care is the advance directive (AD) for health care. AD policies, decision aids for facilitating ADs, and clinical processes for interpreting ADs all treat patients as rational actors who will make appropriate choices, if provided relevant information. We review barriers to following this model, leading us to propose replacing the goal of rational choice with that of *value awareness*, enabling patients (and, where appropriate, their surrogates) to be as rational as they *can and want to be* when making these fateful choices. We propose approaches, and supporting research, suited to individuals' cognitive, affective, and social circumstances, resources, and desires.

Keywords

decision making, end of life, preferences, psychology, serious illness, terminal care

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In the idealized vision of preferences that underlies rational actor models, people know what they want in all possible circumstances. In reality, though, people are not born with well-articulated utility functions applicable to all possible outcomes. Rather, they acquire their preferences through experience and inference. Experience may dominate preference formation for repeated decisions. People come to prefer particular foods through a lifetime of tasting. They come to prefer particular detergents through trial-and-error cleaning experiments. In contrast, inference may dominate unique decisions, such as those involving serious illness and end-of-life care, that force patients to ask, and then answer, often-difficult questions about what matters most to them, in life and in death. What tradeoffs do they want to make between expected discomfort and expected longevity? How important are the resources and memories that they will leave with people close to them? How much responsibility do they want to bear for a fateful decision, added to the weight of living with its consequences?

Here, we consider the relevance of the rational actor model as a standard for serious illness, potentially

requiring end-of-life decisions, in light of the many studies showing the vagaries of preference formation in situations where people may not immediately know what they want. We offer an alternative to the rational actor standard, which we call *value awareness*, for decisions whose cognitive, affective, and social demands make rationality

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an unrealistic or even unwanted goal. Value awareness holds that patients (and their surrogates, where relevant) are best served by having the fullest possible opportunity to be as rational as they can and want to be. After sketching our argument in the next section, we describe the circumstances of end-of-life decisions and their implications for the rational actor model. We propose changes in clinical practice, and supporting research, for achieving value awareness.

Limits to Rational Choice

The barriers to understanding the complex, uncertain, unfamiliar facts regarding medical decisions are well-known and documented. Drawing on basic science in judgment and decision making, medical researchers have made great progress in making facts clearer, assessing the limits to patients' understanding, and characterizing patients' appreciation of those limits. However, better communication may, actually, make decision making harder, by putting difficult choices in sharper relief. Rather than face those choices, patients may look for information about the world, which will somehow clarify matters, when the critical uncertainties lie within them. They may also be vulnerable to manipulation by how a decision is presented, not realizing that there are other ways to look at it, which might lead to different choices.

Anomalies in preference formation have long been a focal topic in behavioral decision research and its precursor fields.^{1,2} Experimental demonstrations have shown how labile preferences can be, in situations where people do not know what they want well enough to resist the manipulations of experimenters, marketers, and others. Context effects, framing effects, priming effects, and preference reversals are among the many ways in which seemingly subtle changes in how options are presented have been found to affect choices.^{3,4} The potential implications of that research for end-of-life decisions are suggested by studies showing the effects of default text on patients' advance directives,⁵ physicians' framing of options on patients' choices between life-supporting and comfort-focused treatments,⁶ physicians' word use on surrogates' cardiopulmonary resuscitation decisions,⁷ and priming on providers' plans to discuss withdrawing life support in the intensive care unit.⁸ Patients are vulnerable to these effects because they lack trial-and-error experience making the decisions. Physicians are vulnerable because, even when they know the procedures and expected outcomes, they may not know the patients and their, perhaps evolving, perspectives.⁹

Given these results from basic research and affirming evidence from medical applications, we propose a shift in the philosophy guiding medical decision making regarding end-of-life care. That shift recognizes both the value and the limits of the rational actor model. It embraces the due diligence that rational analysis requires of health care professionals: to clarify decisions as far as analysis allows. However, it also recognizes that the results of such analyses may overwhelm patients, even when every effort has been made to identify the issues most material to their choices, communicate those issues clearly, and respect patients' conclusions. Our proposed alternative goal, *value awareness*, recognizes these limits and the need for procedures that accommodate them, serving actual patients and not just idealized ones.

Our proposed alternative also recognizes that, cognitive limits aside, not all issues are subject to rational analysis. People may have sacred values that preclude the tradeoffs required by the utility theory axioms that underlie rational actor models. As a result, they do not want to be rational, in the utility theory sense, over option sets where sacred values are at stake. A sacred value familiar to health care providers is the religious prohibition against blood transfusion among Jehovah's Witnesses. People may also have strong preferences for how decisions are made, and not just their expected outcomes, which are all that rational actor models consider. For example, patients may want emotions, faith, fate, or family to guide them, even when they could, rationally, identify the option with the highest expected utility.

We define the alternative goal of *value awareness* as enabling patients to achieve their desired balance between rational and nonrational decision making, allowing them to be *as rational as they can and want to be*. That means doing everything possible to make the critical issues clear, thereby expanding the envelope of potentially rational decision making. It also means allowing patients to determine how far they want to go down the rational-actor path, recognizing that it only considers expected outcomes, and not the process leading to them. Embracing that path fully means making tradeoffs among all possible outcomes, with none being sacred; attaining adequate cognitive mastery of all relevant issues; and willingly bearing personal responsibility for the choices and the outcomes that follow.

The next section briefly reviews the policy framework that posits the rational actor standard for patient decision making. Building on work by Fagerlin,¹⁰ Sudore,¹¹ and others, we examine the challenges to meeting that standard posed by end-of-life decisions and, then, offer value awareness as an alternative standard. We propose

changes in health care practice needed to achieve value awareness and research needed to support those changes. Foremost among the practice changes are ones that give patients confidence that they will receive the cognitive, affective, and social support needed to navigate the path that they choose to travel. Foremost among the research questions are how to afford patients' cognitive understanding of how well they could, conceivably, understand the decisions facing them and affective understanding of how they will feel, given their choice.

The Policy Ideal

In the United States, the principal policy tool for respecting patient's preferences for end-of-life care is the advance directive (AD) for health care. ADs are legal documents (e.g., living wills, durable powers of attorney for health care) to be exercised when individuals cannot make decisions on their own behalf. ADs can indicate medical treatments for circumstances specified in them or designate individuals as proxies for circumstances that are not. Luis Kutner first proposed the AD as an extension of the legal requirement for informed consentⁱ in 1969.¹² In the 1976 Quinlan case, the US Supreme Court affirmed that individuals' right to direct their medical care with ADs was Constitutionally guaranteed. In order to promote AD use, Congress passed the 1990 Patient Self-Determination Act, requiring health care institutions (but not individual clinicians) to provide patients with information about ADs.

ADs treat patients (and their surrogates) as rational actors, who will choose the option with the highest expected utility, if provided needed information. The rational actor model assumes well-formulated decisions, with each option (e.g., treatment) represented as a vector of expected outcomes (e.g., pain, anxiety, life expectancy) that a decision maker can weight by relative importance. Procedures grounded in discrete choice theory have been used to elicit such preferences for end-of-life decisions including choices of health care proxy, treatment regime, and care site (e.g., home, hospital, hospice).^{13,14} One important reason for ADs is that the turmoil of critical medical situations may preclude careful deliberation even when patients are

cognitively competent. In practice, creating ADs, which address future decisions, often loses out in the competition with everyday chores and emergencies.¹⁵

Formal decision aids offer structured ways to formulate ADs, designed to help users overcome the emotional stress of contemplating such events or drifting off because the task becomes bewildering.¹⁶ Such aids can prune overly "bushy" decision trees, highlighting the issues that mattered most to test populations or helping users identify their own priorities. There have been several systematic reviews^{17,18} and one meta-analysis¹⁹ of decision aids' impacts. The evidence suggests that they can increase the probability of patients completing ADs and discussing end-of-life care preferences with health care providers. A few trials have found that aids increased the probability of similar hypothetical choices being made by patients and proxies²⁰ or by patients and providers.²¹ Several trials have found that patients are more likely to receive end-of-life care consistent with an AD created with an aid.²²⁻²⁴ No study has addressed the difficult question of how aids affect the quality of health care and end-of-life experiences.

Barriers to Rational Actor Policies

In addition to providing potentially useful information, decision aids attempt to address a common barrier to rational actor models: the lack of clearly identified decision points, with well-formulated options. Without such junctures, patients (or their surrogates) may find themselves facing critical decisions, such as whether to intubate a patient in acute respiratory distress, under conditions where they lack the time, energy, or focus needed for rational decision making. Or, they may experience social pressures that preclude orderly deliberation, as they try to reconcile the desires and perceptions of family and providers. Or, critical options, outcomes, and uncertainties may end up hidden in plain sight, buried in irrelevant detail or mistakenly treated as "going without saying." In such situations, critical choice points may slip by, leaving patients' fate to standard operating procedures that undermine their autonomy, such as the protocols followed by pre-hospital emergency response teams, emergency departments, or intensive care units.²⁵

Decision aids might address all of these limits. However, their use ignores the possibility that some patients, for some decisions, may prefer a less orderly process, with chances to ruminate about difficult issues and perhaps find ways to work around them. When patients cannot, or will not, think their way through to a choice, decision aids may force their hand, asking them

ⁱ"The patient may not have had, however, the opportunity to give his consent at any point before treatment. He may have become the victim of a sudden accident or a stroke or coronary. Therefore, the suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicated to what extent he would consent to treatment. The document indicating such consent may be referred to as a "living will."^{12(p551)}

to do the impossible. Without the chance to deliberate, patients may make choices without fully knowing what they want and without achieving the consolidated state of mind needed to live with their choices and the outcomes that follow. Value awareness recognizes these possibilities and seeks to expand the envelope of issues that patients can address, without pushing them into territory that they cannot handle.

Relaxing the Rational Actor Model

Rational actor models have no choice but to force the issue and elicit preferences among well-defined options. The essence of rationality is having orderly preferences over the expected outcomes of all available options, with “order” defined by the coherence criteria of the utility theory axioms. The limits to achieving such coherence can be seen in studies eliciting utilities for health states, which typically exclude many responses as deficient for one reason or another.²⁶ The limits might also be seen in studies eliciting preferences for public goods, where participants often give “protest responses,”²⁷ refusing to answer questions that are formally well-structured, but cognitively intractable.

Herbert Simon proposed two reasoned strategies for decisions that are unmanageably diffuse or complex. One is *bounded rationality* (or approximate optimization), making rational choices for a simplified version of the actual decision, deliberately neglecting some options, consequences, or uncertainties. Decision aids for ADs are created in this spirit, focusing patients on the subset of issues that their designers consider most important. These aids fail analytically if they bound the problem inappropriately, missing critical options, outcomes, or uncertainties. They fail behaviorally if they exclude context that patients need to orient themselves within their bounds.

Simon’s second strategy is *satisficing*, which does not explicitly ignore any topic, but abandons the quest for a perfect (rational) choice, seeking instead an acceptable (satisficing) one. Examples related to end-of-life decisions might include discussing advance care planning in general terms or assigning someone durable health care power of attorney, both ways of circumscribing acceptable ways of addressing future contingencies. These strategies fail analytically if the rules do not capture patients’ concerns. They fail behaviorally if patients do not understand the practical implications of their choices.

In Simon’s formulation, the success of simplifying strategies depends on the quality of the heuristics that guide them. Professionals seeking to aid patients can

draw on experience and research, for heuristics regarding the distribution of patient preferences, where individual patients fall in that distribution, what consultative processes leave patients most satisfied with their choices, and how they hold up through the cascades of decisions and outcomes that follow patient choices.¹¹

Patients, however, rarely have experience with once-in-a-lifetime decisions about end-of-life care. They must draw on heuristics acquired in other settings. The validity of those heuristics depends on how similar the options, outcomes, and uncertainties are, as well as whether they can consult (or ignore) similar people, take similar time to digest the issues, trust the same strategies for managing their own emotions, and similarly handle the attendant social pressures. Extending cognitive, affective, and social heuristics beyond their effective range runs the risk of unwelcome, and unwitting, bias. Abandoning them runs the risk of untested improvisation or ceding control to others. Value awareness seeks to take patients as far as they can and want to go toward rational choices, realizing how far they have come and where further efforts would take them. The next section describes it more fully, along with the research needed to realize it—sometimes waiting to be used, sometimes waiting to be conducted.

The Value Awareness Ideal

Cognitive Goals

Patients with value awareness understand their options, the limits to that understanding, and the opportunities to learn more.²⁸ There are vast literatures on how to communicate expected risks and benefits, in terms of both quantitative estimates of expected outcomes and the qualitative processes generating them. Although researchers are continuing to refine these methods, the practical challenge is applying what is known. That effort must include learning enough about patients’ beliefs and values to identify their information needs and evaluating how well the process has succeeded.

Within the rational actor model, success can be addressed with sensitivity analyses, assessing whether additional information would affect choices. Such analyses can also determine whether individuals’ values are sufficiently precise to identify their preferred option. Making choices requires translating general values into preferences among specific options. For example, although pain is important in principle, it should not matter in practice when expected to be similar for all treatment options. Decision aids for rational actors consider how much outcomes vary across options, so as to direct patients’ limited attention to the facts that they

need to know, and away from facts that it would be nice to know or are hardly worth bothering with at all.^{29–32}

Such analyses break down when beliefs or preferences are inconsistent, in the sense of having internal contradictions (e.g., violating the conjunction rule or transitivity axiom). They also break down when beliefs or preferences are incomplete, in the sense of people not knowing what to say. With beliefs, that possibility has prompted the development of non-Bayesian belief functions, such that a portion of a probability distribution remains unallocated, recognizing the possibility of as-yet-unimagined hypotheses or contingencies. With preferences, that means violating the comparability axiom, indicating neither preference nor indifference among options.

Value awareness means recognizing, addressing, and, perhaps, accepting situations where people do not know what to think or want. The research challenge here is developing an empirically and ethically sound approach to reactive measurement, whereby the elicitation process may change people, by suggesting perspectives. Scientifically, much is known about how people construct preferences.^{4,33–37} That research provides a foundation for helping patients articulate the implications of their basic values for end-of-life decisions.³⁸ However, we lack accepted standards for establishing that the elicitation process has deepened patients' understanding rather than biasing it. Absent such standards, decision aid designers may prefer to risk sins of omission, in the sense of leaving patients to the own devices, over sins of commission, in the sense of biasing their responses.

Affective Goals

Patients with value awareness will understand themselves in relationship to their decisions. If they succeed, then they will make decisions that they can live with, confident that they have gone as far as they are comfortable in making sense of the issues and assuming responsibility for what follows.^{2,39,40} One threat to having a warranted feeling of being able to live with a decision-making process comes from failures of metacognition, not realizing how well (or poorly) one has understood the issues. That could lead to searching for missing facts when the residual uncertainties are about values. It could also lead to premature closure, exposing oneself to regret, from missing issues that were there to be found. A second threat is failures of affective forecasting, seen in studies showing that people cannot always predict their pleasure (or pain)⁴¹ nor introspect about the factors shaping their choices.⁴² Difficult choices may demand inferences that defy individuals' inferential abilities, forcing them to rely

on heuristics attuned to more mundane ones. Their judgment may be clouded by irrelevant emotions or insensitive to relevant ones. They may be derailed by contextual cues, such as the reference points of prospect theory.^{3,4} They may not know when they do not know what they want.

Researchers have long recognized that individuals may have *uncertain* values, as seen in models for stochastic preferences (where A is usually preferred to B).⁴³ However, those models do not address *inconsistent* preferences, in the sense of being “of more than one mind” on a topic, or *incomplete* preferences, in the sense of not fully grasping what is at stake, given the novelty, complexity, or contradictions of a choice. Unless a decision-making process allows participants to recognize and resolve inconsistent and incomplete preferences, it risks misrepresenting their views. It must then balance pressing too hard, forcing people to deal with issues that they cannot handle, and not pressing hard enough, leaving superficially orderly preferences.

Once, psychologists distinguished cold and hot cognition, referring to behavior driven by thought and emotion, respectively. The two are now seen as intertwined. On the one hand, emotion is a natural part of thought,⁴⁴ with affective reactions sometimes preceding and directing cognitive ones. On the other hand, cognitive expectations and contextual cues can shape how people interpret affective arousal. Emotions can aid cognition, by orienting people to the content of messages. Emotions can also degrade cognition, by distorting or blocking that content. How much emotions matter depends on the size of these effects. It also depends on how emotions affect decision makers' willingness to rely on thought, rather than feeling. That should depend, in turn, on how well their cognitive needs have been satisfied, so that they can think their way to reasoned choices, rather than drift into crises or act out in frustration. Value awareness builds on this research to take patients to the most comfortable spot, in what might be painful terrain.

Social Goals

Patients with value awareness will understand the roles that they wish to have others play in their decision-making process. Health care staff are one set of others. Family members are a second. Decision aids (and aides) are a third. In each case, patients want some forms of support from those others, while preserving some measure of autonomy. In each case, those others may have useful perspectives, potentially clouded by their own interests and experiences. In each case, the relationships

are both a means to better decisions and an end, shaping how patients live their final days.

Rational actor models might accommodate some of these concerns as additional outcomes. For example, some patients might willingly sacrifice physical comfort in order to secure peace in the family or satisfy a loved one's religious preferences. Other concerns, though, might raise ethical flags. For example, "making the doctors happy" might not be a legitimate goal, even if it were done with the instrumental goal of hoping to secure better care. Still other concerns refer to the decision-making process, with no direct or indirect effect on outcomes, hence have no place in rational actor models.

Achieving value awareness means helping patients understand and manage these processes. The needed research would, in effect, make them better intuitive social psychologists, organizational scientists, anthropologists, and so on, when answering questions such as the following: Who are these people? What are their goals? How far do they share mine? What will they do when our goals conflict? How well do they understand me? How can I enlist their engagement, or get them to back off? What will they assume, if I appear hesitant (or confident)? What standard operating procedures will take over if I fail to act?

Value Awareness in Practice

Our advocacy of value awareness makes explicit an emerging shift in clinical practice. While this shift reflects interdisciplinary efforts from practitioners in multiple specialties, including geriatrics and critical care, the new specialty of palliative care is perhaps most closely associated with it. Palliative care best practice encourages clinicians to elicit general goals and values, rather than specific preferences; use scenario planning to examine downstream decisions; explore tradeoffs via deliberation; and acknowledge uncertainty. Such best practice is also increasingly willing to offer treatment recommendations, reflecting what clinicians believe patients would want, were they to achieve value awareness. By acknowledging the difficulty of these decisions, such consultations may relieve some of the moral and emotional burden⁴⁵⁻⁴⁹ that currently falls on patients, surrogates, and providers, protecting them from stress⁵⁰ and burn-out.⁵¹⁻⁵³

As an example, consider the case of a 75-year-old, formerly independent woman, who initially presented with a stroke causing right-sided hemiparesis (inability to move her right arm and leg), aphasia (inability to speak), and difficulty swallowing. She had a living will stating

that if she were "terminally ill" or in a "permanent coma" she did not want life-sustaining treatment, such as cardiopulmonary resuscitation, mechanical ventilation, or a feeding tube. Although she recovered sufficiently after 3 days to track people in the room with her eyes and answer some "yes/no" questions, she remained somnolent. The neurology team reported that the full extent of her cognitive and functional recovery was hard to predict. However, it would require time in an inpatient rehabilitation facility. Transfer to that facility would require a feeding tube to provide nutrition because she could not yet swallow without aspirating (breathing food into her lungs). The alternative would be supportive care with home- or facility-based hospice. She has adult children, one of whom, a daughter, is her designated decision maker. That daughter is asked to make a decision about feeding tube placement on hospital day 3.

With a rational actor approach, the neurologist might offer a clear contextual cue: the patient "needs" an (enteral) feeding tube. A surgeon or gastroenterologist would then request written informed consent for that specific procedure. That narrow decision would not consider outcomes other than the immediate risks and benefits, nor would it consider downstream decisions, such as whether to discontinue enteral feeding in the absence of functional recovery.⁵⁴ At least one decision aid exists to help surrogates make feeding tube decisions for older adults.^{55,56} Were it used in this case, the woman's surrogate might achieve value awareness for the boundedly rational decision that it poses. That is, she could understand its issues, feel at peace with her choice, and manage the social interactions with staff and other family members.

That equanimity might break down, though, if staff presented the cascade of decisions that might arise, depending on her mother's progress. That reality could threaten all three aspects of value awareness. Cognitively, there might be more contingencies than she could keep in mind. Affectively, the potential consequences might be more dire than she could bear. Socially, she might struggle to convene the staff needed to inform her choice or convince her siblings that she can interpret their mother's longer-term wishes.

A value awareness approach to this choice might involve a facilitated conversation with a palliative care specialist or non-specialist provider trained in the Serious Illness Conversation Guide.⁵⁷ The guide outlines a semi-structured interview process designed to understand the patient's values and goals (e.g., critical abilities she would not wish to live without; willingness to accept burdensome treatment for life extension), discusses prognostic expectations and uncertainty, explores and validates

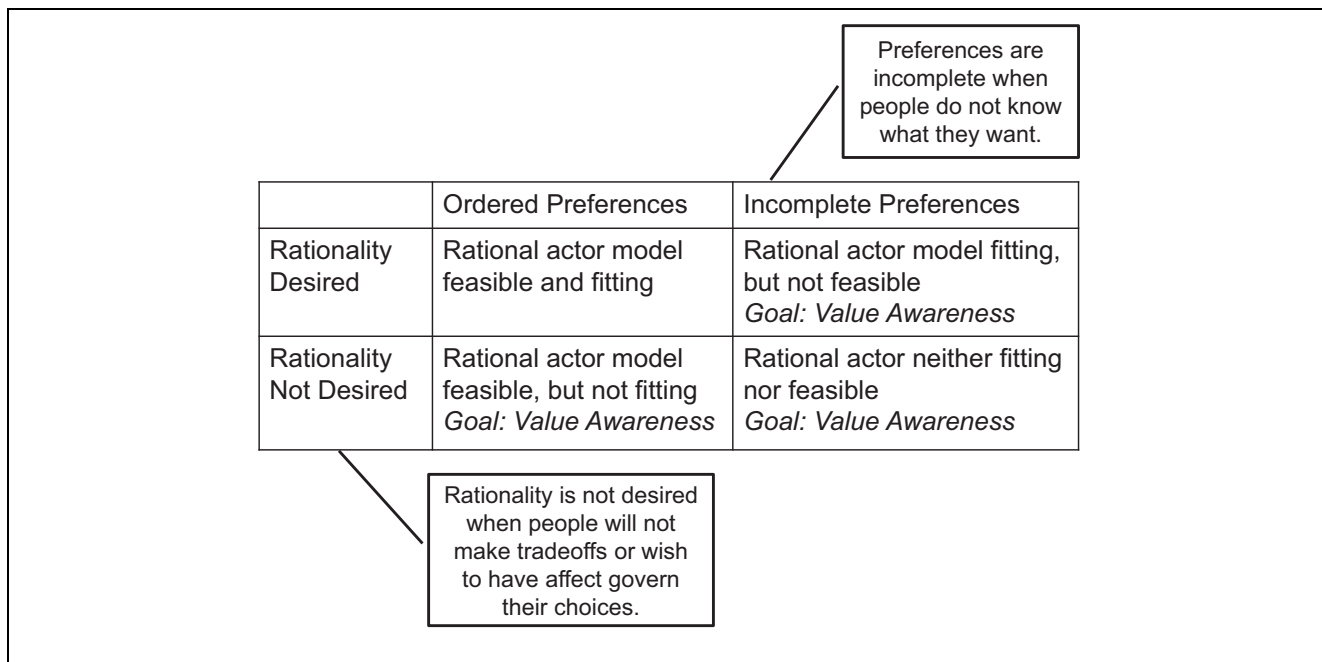


Figure 1 Value awareness: A goal for end-of-life decision making. This schematic summarizes the feasibility and suitability of the rational actor model under different decision making conditions. It offers an alternative goal, value awareness, in situations common to end-of-life decisions.

emotions, and supports deliberations. These interviews are structured to identify differences in patient and the surrogate preferences, so as follow the former, while recognizing the reality (and humanity) of the latter. In these ways, the protocol places the narrow treatment decision (about the feeding tube) in the broader context of the patient’s treatment strategy. This approach would achieve value awareness if the surrogate understands the facts of her mother’s circumstances, feels emotionally supported in making the choices, and has confidence in her ability to navigate the system and her family’s dynamics.

Conclusions

Informed consent has long provided the ethical foundation for US medical practice, especially for high-stakes decisions, such as those arising with serious illness and end-of-life care. The rational actor model has long guided explication of the informed consent principle, providing a framework for identifying facts and values that patients (or their surrogates) might wish to consider. ADs and decision aids have translated those analyses into practice. Practitioners have accumulated valuable experience with them.

In parallel with these clinical developments, basic behavioral research has exploded, documenting challenges to rational actor schemes, including cognitive

limits to information processing and affective and social pressures on decision making. The complex, diffuse ways in which serious illness and end-of-life decisions emerge and evolve^{25,58-61} often represent extreme versions of these challenges. Burgeoning professional and popular literatures document these limits.⁶²⁻⁶⁸

We propose value awareness as an alternative to the rational actor model. It embraces that model’s commitment to rigorous analysis of what is and what could be known about a medical condition and treatment options. However, it also maintains realistic aspirations for how far that analysis can and should go with end-of-life choices. For well-formulated decisions, the rational actor model may be feasible, especially with proposed reforms in health care practices, such as shared decision making and greater primary palliative care capacity.^{69,70} Examples might include decisions about cardiopulmonary resuscitation in the event of a full cardiorespiratory arrest or the initiation of a time-limited trial of mechanical ventilation for respiratory failure. However, the model breaks down when patients (or their surrogates) lack clear decision points, adequate understanding of the issues, the ability to reconcile inconsistent or incomplete preferences, or the ability to bear full responsibility for their choices. With unfamiliar, evolving fateful end-of-life decisions, those may be more common. Examples might include

decisions about discontinuing of life-supporting therapy in the intensive care unit after a complication of major surgery or discontinuing systemic cancer therapy and enrolling in hospice in the context of advanced cancer.

To address those decisions, health care systems need an alternative. We propose that of value awareness. Grounded in behavioral decision research, it seeks to extend the range of the rational actor model as far as possible, while delineating and addressing its limits (Figure 1). It is supported by research that integrates analytical and behavioral components. The analytical component identifies the elements of decisions that lend themselves to rational actor choices and structures the bounded rationality approaches of decision aids and the satisficing approaches of advance directives. The behavioral component develops better ways to communicate uncertain risks and benefits, help people articulate and express their preferences, and manage the social processes swirling around these choices.

Achieving these policy and research goals requires collaboration between scientists and practitioners, in order to relax the analytical rigidity of the rational actor model in disciplined ways. Approaches might include the Serious Illness Conversation Guide (discussed above), curated narratives of others' decisions, and decision aids illustrating alternative heuristic rules. The rational actor model has taken us a long way toward addressing the needs of patients facing end-of-life decisions. Another model is needed to take us beyond its limits. We propose that of value awareness, using analytically informed and behaviorally realistic approaches to aid patients and proxies with these most difficult decisions. Value awareness is achieved when decision makers have gotten as far as they can go and want to go in articulating their preferences, and feel as confident as possible in being able to weather the affective and social pressures of what lies ahead.

References

- Fischhoff B, Manski C. The elicitation of preferences. *J Risk Uncertain*. 1999;19:1–3.
- Lichtenstein S, Slovic P, eds. *The Construction of Preference*. New York: Cambridge University Press; 2006.
- Fischhoff B, Slovic P, Lichtenstein S. Knowing what you want: measuring labile values. In: Wallsten T, ed. *Cognitive Processes in Choice and Decision Behavior*. Hillsdale: Lawrence Erlbaum; 1980. p 117–41
- Kahneman D. *Thinking, Fast and Slow*. New York: Farrar, Giroux & Strauss; 2011.
- Halpern SD. Employing behavioral economics and decision science in crucial choices at end of life. *Health Aff (Millwood)*. 2012;31(12):2789–90.
- Lu A, Mohan D, Alexander SC, Mescher C, Barnato AE. The language of end-of-life decision making: a simulation study. *J Palliat Med*. 2015;18(9):740–6.
- Barnato AE, Arnold RM. The effect of emotion and physician communication behaviors on surrogates' life-sustaining treatment decisions: a randomized simulation experiment. *Crit Care Med*. 2013;41(7):1686–91.
- Turnbull AE, Krall JR, Ruhl AP, et al. A scenario-based, randomized trial of patient values and functional prognosis on intensivist intent to discuss withdrawing life support. *Crit Care Med*. 2014;42(6):1455–62.
- Barnato AE. Challenges in understanding and respecting patients' preferences. *Health Aff (Millwood)*. 2017;36(7):1252–7.
- Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep*. 2004;34(2):30–42.
- Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*. 2010;153(4):256–61.
- Kutner L. Due process of euthanasia: the living will, a proposal. *Indiana Law J*. 1969;44(4):539–54.
- Elwyn G, O'Connor A, Stacey D, et al; International Patient Decision Aids Standards (IPDAS) Collaboration. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ*. 2006;333(7565):417.
- Llewellyn-Thomas HA, Crump RT. Decision support for patients: values clarification and preference elicitation. *Med Care Res Rev*. 2013;70(1 suppl):50S-79S.
- Halpern SD. Shaping end-of-life care: behavioral economics and advance directives. *Semin Respir Crit Care Med*. 2012;33(4):393–400.
- Simon HA. Rational choice and the structure of the environment. *Psychol Rev*. 1956;63(2):129–38.
- Butler M, Ratner E, McCreedy E, Shippee N, Kane RL. Decision aids for advance care planning: an overview of the state of the science. *Ann Intern Med*. 2014;161(6):408–18.
- Weathers E, O'Caoimh R, Cornally N, et al. Advance care planning: a systematic review of randomised controlled trials conducted with older adults. *Maturitas*. 2016;91:101–9.
- Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc*. 2014;15(7):477–89.
- Song MK, Kirchoff KT, Douglas J, Ward S, Hammes B. A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. *Med Care*. 2005;43(10):1049–53.
- Levi BH, Heverley SR, Green MJ. Accuracy of a decision aid for advance care planning: simulated end-of-life decision making. *J Clin Ethics*. 2011;22(3):223–238.
- Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.

23. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a disease-specific advance care planning intervention on end-of-life care. *J Am Geriatr Soc.* 2012;60(5):946–50.
24. Morrison RS, Chichin E, Carter J, Burack O, Lantz M, Meier DE. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *J Am Geriatr Soc.* 2005;53(2):290–4.
25. Kaufman SR. *And a Time to Die: How American Hospitals Shape the End of Life.* Chicago: University of Chicago Press; 2005.
26. Engel L, Bansback N, Bryan S, Doyle-Waters MM, Whitehurst DG. Exclusion criteria in National Health State Valuation Studies: a systematic review. *Med Decis Making.* 2016;36(7):798–810.
27. Pennington M, Gomes M, Donaldson C. Handling protest responses in Contingent Valuation Surveys. *Med Decis Making.* 2017;37(6):623–34.
28. Fischhoff B, Kadavy J. *Risk: A Very Short Introduction.* Oxford: Oxford University Press; 2011.
29. Raiffa H. *Decision Analysis: Introductory Lectures on Choices Under Uncertainty.* Reading: Addison-Wesley; 1968.
30. Krishnamurti T, Argo N. A patient-centered approach to informed consent: results from a survey and randomized trial. *Med Decis Making.* 2016;36(6):726–40.
31. Merz JF, Fischhoff B, Mazur DJ, Fischbeck PS. Decision-analytic approach to developing standards of disclosure for medical informed consent. *J Toxics Liability.* 1993;15(1):191–215.
32. Fischhoff B. The sciences of science communication. *Proc Natl Acad Sci U S A.* 2013;110(Suppl. 3):14033–9.
33. Kahneman D, Slovic P, Tversky A. *Judgment Under Uncertainty: Heuristics and Biases.* Cambridge: Cambridge University Press; 1982.
34. Johnson-Laird P. *How We Reason.* Oxford: Oxford University Press; 2006.
35. Klahr D. What do we mean? On the importance of not abandoning scientific rigor when talking about science education. *Proc Natl Acad Sci U S A.* 2013;110(Suppl. 3):14075–80.
36. Klahr D, Simon HA. Studies of scientific discovery: complementary approaches and convergent findings. *Psychol Bull.* 1999;125:524–43.
37. Craik KJW. *The Nature of Explanation.* Cambridge, England: Cambridge University Press; 1943.
38. Fischhoff B, Brewer N, Downs JS. *Communicating Risks and Benefits: An Evidence-Based User's Guide.* Washington: US Food and Drug Administration; 2011.
39. Bettman JR, Luce MF, Payne JW. Constructive consumer choice processes. *J Consum Res.* 1998;25:187–217.
40. Fischhoff B. Value elicitation: is there anything in there? *Am Psychol.* 1991;46(8):835–47.
41. Gilbert DT, Wilson TD. Miswanting: some problems in the forecasting of future affective states. In: Forgas J, ed. *Feeling and Thinking: The Role of Affect in Social Cognition.* Cambridge, England: Cambridge University Press; 2000. p 178–97.
42. Nisbett RE, Wilson TD. Telling more than we can know: verbal reports on mental processes. *Psychol Rev.* 1977;84(3):231–59.
43. Coombs C. *A Theory of Data.* New York: Wiley; 1964.
44. Slovic P, ed. *The Feeling of Risk.* New York: Earthscan; 2010.
45. Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med.* 2011;154(5):336–46.
46. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. *Crit Care Med.* 2012;40(2):618–24.
47. Azoulay E, Pochard F, Kentish-Barnes N, et al; FAM-IREA Study Group. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med.* 2005;171(9):987–94.
48. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med.* 2007;356(5):469–78.
49. Pochard F, Darmon M, Fassier T, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *J Crit Care.* 2005;20(1):90–6.
50. Lamiani G, Borghi L, Argentero P. When healthcare professionals cannot do the right thing: a systematic review of moral distress and its correlates. *J Health Psychol.* 2017;22(1):51–67.
51. Embriaco N, Papazian L, Kentish-Barnes N, Pochard F, Azoulay E. Burnout syndrome among critical care healthcare workers. *Curr Opin Crit Care.* 2007;13(5):482–8.
52. Embriaco N, Azoulay E, Barrau K, et al. High level of burnout in intensivists: prevalence and associated factors. *Am J Respir Crit Care Med.* 2007;175(7):686–92.
53. Poncet MC, Toullic P, Papazian L, et al. Burnout syndrome in critical care nursing staff. *Am J Respir Crit Care Med.* 2007;175(7):698–704.
54. Taylor LJ, Nabozny MJ, Steffens NM, et al. A framework to improve surgeon communication in high-stakes surgical decisions: best case/worst case. *JAMA Surg.* 2017;152(6):531–8.
55. Mitchell SL, Tetroe J, O'Connor AM. A decision aid for long-term tube feeding in cognitively impaired older persons. *J Am Geriatr Soc.* 2001;49(3):313–6.
56. Mitchell SL, Tetroe J, O'Connor AM, Rostrom A, Villeneuve C, Hall B. Long-term feeding tube placement in the elderly. Available from https://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf
57. Ariadne Labs. *Serious Illness Conversation Guide.* Boston: Ariadne Labs; 2017.
58. Butler K. What broke my father's heart. *The New York Times Magazine.* Available from: <https://www.nytimes.com/2010/06/20/magazine/20pacemaker-t.html>
59. Butler K. *Knocking on Heaven's Door: The Path to a Better Way of Death.* New York: Scribner; 2013.

60. Gawande A. *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books; 2014.
61. Nuland SB. *How We Die*. New York: Random House; 1995.
62. Barnato AE, Mohan D, Lane RK, et al. Advance care planning norms may contribute to hospital variation in end-of-life ICU use: a simulation study. *Med Decis Making*. 2014;34(4):473–84.
63. Barnato AE, Tate JA, Rodriguez KL, Zickmund SL, Arnold RM. Norms of decision making in the ICU: a case study of two academic medical centers at the extremes of end-of-life treatment intensity. *Intensive Care Med*. 2012;38(11):1886–96.
64. Barnato AE, Herndon MB, Anthony DL, et al. Are regional variations in end-of-life care intensity explained by patient preferences? A study of the US Medicare population. *Med Care*. 2007;45(5):386–93.
65. Nicholas LH, Langa KM, Iwashyna TJ, Weir DR. Regional variation in the association between advance directives and end-of-life Medicare expenditures. *JAMA*. 2011;306(13):1447–53.
66. Bernstein N. Fighting to honor a father's last wish: to die at home. Available from: <https://www.nytimes.com/2014/09/26/nyregion/family-fights-health-care-system-for-simple-request-to-die-at-home.html>
67. Brenoff A. Efforts to prolong my husband's life cost him an easy death. Death isn't a four-letter word, and doctors need to learn that. *The Huffington Post*. Available from: https://www.huffingtonpost.in/entry/end-of-life-care_us_5878344be4b0b3c7a7b0aac6
68. Shakerdge K. A dying man's wish to save others hits hospital ethics hurdle. *Kaiser Health News*. Available from: <http://khn.org/news/a-dying-mans-wish-to-save-others-hits-hospital-ethics-hurdle/>
69. Lee EO, Emanuel EJ. Shared decision making to improve care and reduce costs. *N Engl J Med*. 2013;368(1):6–8.
70. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med*. 2015;373(8):747–55.