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Challenges In Understanding And Respecting Patients' Preferences

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ABSTRACT The Institute of Medicine's report on *Dying in America* called for honoring treatment preferences near the end of life for seriously ill patients. To achieve this objective, the report recommended that patients, their family members, other loved ones, and providers engage in shared decision making about current and future treatment decisions (that is, advance care planning). Yet decision science research suggests that preferences are objectively difficult to specify for complex contingencies and subjectively difficult to specify for unfamiliar choices. Because advance care planning involves both difficulties—the future may unfold in complex ways and pose unprecedented choices—it may not fully and faithfully specify patients' preferences. I discuss a powerful but overlooked influence on this planning: local providers' practice norms. Norms often begin as generally accepted procedures but evolve into rules enforced by both external and internal sanctions (such as shame and pride). Local practice norms regarding the timing, content, and interpretation of advance care planning conversations influence patient choice. While the influence of providers on patients' decisions cannot be entirely removed, I recommend increasing providers' awareness of this influence by using audit, feedback, and coaching and by systematizing processes for advance care planning.

The Institute of Medicine's 2015 report *Dying in America* was subtitled *Improving Quality and Honoring Individual Preferences Near the End of Life*.¹ The principal recommendation for honoring treatment preferences was for seriously ill patients, their family members, other loved ones, and health care providers to engage in shared decision making about current and future treatment decisions. Since some of the decisions are about future treatment, this process is called advance care planning. Both shared decision making and advance care planning have evolved over the past decade to extend beyond well-articulated choices—for example, surgery versus radiation for cancer, or whether

or not to use cardiopulmonary resuscitation (CPR) in the event of cardiac arrest—to a philosophy of communication and decision making across the continuum of a patient's medical treatment. Thought leaders now define *advance care planning* as an ongoing process involving conversations about goals of care, life support and resuscitation, palliative care alternatives, principles of surrogate decision making, and formal advance directives.^{2,3}

There have been several recent systematic reviews of the state of the science of advance care planning,^{4,5} narrative reviews of challenges faced by advance care planning and advance directives from a decision science perspective,^{6,7} and systematic reviews of provider barriers to advance

care planning^{8,9} and to including patients' preferences in decision making more broadly.¹⁰ Advance care planning increases the completion of written advance directives and may increase concordance between patients' preferences for care and the care that is delivered.^{4,5} It may also reduce family distress associated with surrogate decision making.¹¹ However, there is only weak evidence that advance care planning can reduce service use and end-of-life spending.^{4,12}

Reviews cite practical and psychological challenges to advance care planning. Angela Fagerlin and Carl Schneider describe the reality that the provisions of many living wills—a form of advance directive—do not apply to the clinical realities many patients face.⁶ For example, few people experience a persistent coma. Also, the definition of *terminal illness* is open to subjective interpretation, depending upon the time horizon. A patient might have incurable metastatic cancer with a few months' life expectancy, but he or she might recover from a bout of pneumonia with a course of antibiotics and life support in the intensive care unit (ICU). Fagerlin and Schneider question the very premise that people can “conjure up preferences for an unspecified future confronted with unidentifiable maladies with unpredictable treatments.”^{96(p33)}

Scott Halpern picks up on Fagerlin and Schneider's arguments about affective forecasting errors in his excellent summary of the psychological biases that undermine engagement in, and the potential validity of, advance care planning.^{7,13} Affective forecasting errors¹⁴—also called “miswanting”—describe people's inability to correctly predict what they will want in a future state. People incorrectly predict what they will want when faced with pain¹⁵ and whether they will find a compromised cognitive or functional state to provide a tolerable quality of life.¹⁶ Indeed, with respect to decrements in function, the psychological literature suggests that people adapt to new states and maintain a relatively stable assessment of their own quality of life. This is called hedonic adaptation.¹⁷

While these affective forecasting errors appear to undermine the validity of advance directives prepared by healthy adults, a systematic review of the literature suggests that preferences for life-sustaining treatment among older adults and people with serious illnesses are actually relatively stable over time.¹⁸ Nevertheless, as a result of these concerns, advance care planning has moved away from fixed statements of future medical treatment preferences and toward patient-provider and patient-surrogate conversations focused on goals of treatment. Goals can be related to function (for example, “life is worth living as long as I can walk my dogs or play

with my grandchildren”) or milestones (such as “I want to live long enough to attend my daughter's wedding”). The hope is that once a patient's goals are made explicit, then the medical team can make treatment recommendations that are most likely to allow the patient to achieve those goals. Board-certified palliative care providers can skillfully engage in these patient-centered conversations. However, this vision is still aspirational in most medical practice.

Barriers to physicians' engagement in advance care planning include lack of time; lack of communication competency, particularly with respect to risk communication and managing emotion;⁸ discomfort with situations in which patients' preferences differ from those of their physicians (or from guidelines); and the physician's desire to retain power in the doctor-patient relationship.¹⁰ Additional structural barriers include difficulty in communicating preferences across sites of care.⁹

In this article I explore the less frequently discussed concern that prevailing provider practice norms shape the timing, content, and interpretation of advance care planning conversations. Norms are generally-agreed-upon rules of behavior that are enforced by sanctions. When norms are so strongly internalized that they become enforced by internal sanctions (such as shame or pride), they become values. I integrate findings from controlled experimental settings, claims-based observational research, and ethnography to explain how local provider practice norms regarding advance care planning likely influence patients' treatment preferences. Specifically, these norms influence the timing and the option space (that is, the choices considered) for treatment preference conversations. To explore this topic, I first summarize the theory of preference construction. I then discuss the mechanisms by which local practice norms might influence preference construction, and I conclude with some recommendations for addressing the concern that patients' treatment preferences are shaped and constrained by prevailing provider practice norms.

Preference Construction

People lack the trial-and-error experience with serious illness decision making that they would require to form stable, informed preferences for complex and potentially fateful end-of-life decisions. People do not commonly confront, for example, decisions such as whether to try another line of chemotherapy or whether to accept a trial of mechanical ventilation for pneumonia with respiratory failure. When faced with such unfamiliar decisions, people's choices can shift

with subtle, seemingly irrelevant, changes in how options are presented.^{19,20} In his influential 1995 article “The Construction of Preference,” Paul Slovic asks: “If different elicitation procedures produce different orderings of options, how can preferences be defined and in what sense do they exist?”²¹ Examples of seemingly irrelevant changes include context effects, framing effects, and priming effects.

The term *context effects* refers to the ways in which environmental factors affect perception. For example, under controlled experimental conditions, patients with advanced lung disease are more likely to choose comfort-focused treatment on an advance directive when it is listed first on the form.²² The term *framing effects* refers to situations where otherwise equivalent descriptions of a choice lead to systematically different choices. Types of framing include attribute framing (giving a choice a positive or negative valence), risky choice framing (emphasizing the loss or the gain), and goal framing (focusing on the advantages of doing versus the disadvantages of not doing). For example, in a simulated family meeting, surrogate decision makers are less likely to choose CPR after cardiac arrest for a critically ill person when the physician describes the alternative to CPR as “allow natural death” instead of “do not resuscitate.”²³ The term *priming effects* refers to the phenomenon in which exposure to one stimulus influences the response to another. Priming is believed to act through implicit memory or association. For example, in a controlled experimental setting, physicians are more likely to express intent to discuss withdrawal of life support with the family of a critically ill patient if they are asked (via an experimental survey prompt) to think about the patient’s functional prognosis before the encounter than when they are not asked.²⁴

These experiments all show, under randomized conditions, that a preference can be manipulated (or “reversed”) with context, framing, and priming. In economics, this is called a “preference reversal.” Preference reversals upset a fundamental axiom of rational choice theory: inviolability. More than three decades of research on preference reversals has given rise to the theory that people “construct” their preferences when they are faced with an unfamiliar choice.²⁵ In this context, *construct* means that people do not have a clear choice already formulated in their mind and instead construct (or build) a choice on the spot. They use various mental shortcuts (or heuristics), guided by both informational (cognitive) and emotional (affective) context cues, to help in the construction.

These heuristics are automatic, efficient, and—when honed through experience and

feedback—highly accurate.²⁰ However, when they are not honed through experience, heuristics can introduce bias. For example (drawing on the previous experimental examples), the choice listed first on the advance directive form may have been chosen more often because one cognitive shortcut is to choose the first item in a list. CPR may have been chosen more often in the family meeting when “do not resuscitate” was the alternative (versus “allow natural death”) because one affective shortcut is to reject options that evoke a negative affective response. Given that minor changes in how options are presented in experimental conditions influence preferences, it is easy to imagine how the more numerous variations in how options are presented in real-world clinical conditions might also.

Decision Recognition

The first major challenge to understanding and respecting seriously ill patients’ preferences is the recognition by patients and providers that a significant decision needs to be made. Only after such recognition can patient and provider move on to the process of shared decision making—a process that includes both sides’ discussing options and outcomes, understanding patients’ values and preferences, and incorporating them into the decision.²⁶

Most patients with a serious illness become aware that a treatment decision must be made only when a provider perceives that there is a decision to make and offers a signpost such as, “We have a decision to make,” or “We have several options to consider.” Some decision points are difficult to clearly demarcate, as in the cases of decisions about continuing, stopping, or postponing noncurative chemotherapy.²⁷ Even when an obvious decision point exists, powerful defaults may operate, so the choice is made implicitly. For example, in a recent study of 2,115 non-comatose older adults with an indication for ICU admission evaluated in fifteen emergency departments, only 12.7 percent were asked for their preference regarding transfer to an ICU.²⁸ In other words, ICU admission for sick patients was such a powerful default that providers often did not present it to patients as a choice at all. Moreover, when providers do make decision points explicit to their patients, the language providers use—including the order in which choices are mentioned and the words used to describe them (for example, referring to a patient’s “need” to be intubated or saying that a patient “could” consider comfort measures)—offer obvious contextual cues.²⁹

Little is known about how physicians decide it is time for advance care planning conversations.

Guidelines recommend that this planning should occur iteratively as the patient's health status changes. Important triggers include aging (which prompts the "welcome to Medicare" wellness visit), a diagnosis of serious illness (such as advanced cancer, dementia, or organ failure), and progressing illness severity (for example, treatment nonresponse and declines in cognitive and functional status).

Practically, however, physicians' attention to advance care planning increases when they perceive that a patient is nearing the end of life. Patients generally assume that physicians will initiate discussions when they are needed.³⁰ Therefore, a physician's judgments regarding when a patient is near the end of life are key to advance care planning. An ethnography of hospital-based decision making suggested that providers decide when it is "time to die" and then initiate conversations about treatment limitation.³¹ By having the conversation only when they think it is time to limit treatment, providers implicitly assert their own goals and values.

Shared decision making theory and best practice in palliative care posit that the threshold for having a conversation about treatment limitation ought to be patient specific—that is, different patients have different goals and therefore will have different attitudes regarding the burden of treatment they are willing to accept.³² But in practice, this threshold for beginning the conversation varies by provider. For example, my coauthors and I found that differences in the determination of "dying" among hospital-based providers (which was the implicit threshold for initiating conversations about limiting life-sustaining treatment in the ICU) helped explain differences in end-of-life care at two of the "top 10" medical centers—one of which delivered low-intensity care, while the other delivered high-intensity care.^{33,34} At the high-intensity center, a patient was considered to be "dying" when he or she could no longer be kept alive despite maximal life support, whereas at the low-intensity hospital, a patient was "dying" when he or she had an underlying terminal illness (for example, metastatic cancer or liver failure without the promise of a transplant) or a profoundly compromised quality of life (such as being in a persistent coma after a stroke).

Value Recognition

Implicitly, then, providers' values determine when it is time to consider (or actively shape) seriously ill patients' "preferences" in medical decision making. And once considered, the same preferences stated in an advance directive can be interpreted differently.³⁵ This is illustrated by

systematic variation between individual hospitals³⁶ and ICUs³⁷ in the likelihood of a patient's receiving life-sustaining treatments such as CPR when he or she has a preexisting treatment limitation, such as a do-not-resuscitate order.

As an example of how this might occur, in the case study of the two academic medical centers mentioned above, my coauthors and I found that intensivists at the high-intensity hospital tended to interpret advance directives narrowly, as statements about what patients were not willing to accept if survival to discharge were impossible—whereas intensivists at the low-intensity hospital tended to interpret advance directives broadly, as statements about what patients were not willing to accept if longer-term survival or return to function were impossible.³⁴ These variations in local provider practice norms may explain why regional variations in end-of-life treatment intensity exist, even though patients in those regions endorse similar goals and treatment preferences when reflecting on what they would want in the event of a serious illness with a life expectancy of one year or less.³⁸

Finally, when providers do discuss a patient's goals and values to guide decision making, they tend to focus on a narrow set of biomedical concerns. In one study of seventy-one family meetings to discuss an incapacitated patient in five ICUs at two medical centers, the values most commonly discussed included longevity, bodily integrity, and symptom palliation.³⁹ In the vast majority of meetings, there were no conversations about the patient's values regarding autonomy and independence, emotional well-being and relationships, physical function, cognitive function, or spirituality—concerns that seriously ill patients identify as being most important to them at the end of life.⁴⁰

Recommendations

Since individuals construct preferences for unfamiliar decisions and since local practice norms create the context for this preference construction, it follows that patients' treatment preferences are often shaped by local practice patterns. Ongoing educational efforts by specialty palliative care providers to train health care professionals to explore patients' broader goals and core values instead of their narrow treatment preferences are an important strategy for addressing this concern. This strategy assumes that these goals and values predate the patient's interactions with the health care system. If so, they may be much less susceptible to influence than medical treatment preferences are.

However, before engaging in conversations focused on patients' goals and values, providers

must first recognize that it is “time” for such conversations. To address this more fundamental concern, I recommend health system investment in advance care planning quality improvement as well as investment by governments and foundations in research to promote the dissemination of this vision of goals-focused planning.

Quality improvement efforts should focus on increasing providers' awareness of the heterogeneity of clinical practices related to the timing, content, and interpretation of advance care planning. Strategies to increase awareness include audit, feedback, and peer coaching. Audit refers to measuring the occurrence of advance care planning in practice, via chart review, direct observation, or patient reports. Feedback refers to a systematic process of reporting back to the provider a summary of the provider's own advance care planning practices. This can occur with or without social comparisons to peers or guideline recommendations. Peer coaching refers to practice observation by a peer who can provide immediate constructive feedback and support the establishment of individualized learning and practice improvement goals.

Quality improvement efforts should also focus on systematizing processes for shared decision making and advance care planning, instead of leaving those processes to providers' implicit judgments. For example, health care systems could implement processes whereby advance care planning is automatically triggered based on objective criteria such as diagnosis, phase in the treatment trajectory, or prognosis. Additionally, health care systems might invest in specially prepared staff members (some have called these people “discussionists”) to facilitate advance care planning discussions^{9,41} or augment planning conversations with standardized, video-based descriptions of treatment options that strive to maintain balance and have been shown to increase patient and family comprehension.⁴²

Efforts to shift payment models from volume to value, such as the CMS Oncology Care Model⁴³ and other bundled payment initiatives, may create incentives to implement these strategies.

Researchers should focus on developing and testing interventions that modify local practice norms. For example, social marketing could be used to increase awareness by patients, families, and providers of harms associated with delaying advance care planning conversations. Social marketing could also be used to craft messages to providers that might accompany their audit and feedback reports. These messages could communicate social approval of early, frequent, and goal-oriented advance care planning conversations and disapproval of late, narrow, and treatment preference-focused conversations.

Additionally, researchers should test pragmatic strategies that could be used to train providers to explore patients' goals and values and to use those values to guide treatment decision making. One such strategy is the serious illness conversation guide developed by Susan Block and Atul Gawande,⁴⁴ a one-page step-by-step guide (including specific words to use) for providers to follow when having conversations about goals of treatment with patients facing serious illness. Another is the best-case/worst-case tool developed by Margaret Schwarze and colleagues,⁴⁵ a narrative approach with an associated pictograph that surgeons can use when having conversations about the best, worst, and most likely outcomes of high-risk surgery for older adults. These structured conversation guides can be used with more time-intensive communication skills training curricula that demand at least one day of role-play practice.⁴⁶ To the extent that such strategies can improve the quality of patient-provider communication, efforts to collect and report real-time patient experience ratings may create incentives for such training.⁴⁷ ■

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NOTES

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