

# Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

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The traditional objective of advance care planning has been to have patients make treatment decisions in advance so that clinicians can attempt to provide care consistent with their goals. The authors contend that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions. They provide practical steps for clinicians to help patients and surrogate decision makers achieve this objective in the outpatient setting. Preparation for in-the-moment decision making shifts the

focus from having patients make premature decisions based on incomplete information to preparing them and their surrogates for the types of decisions and conflicts they may encounter when they do have to make in-the-moment decisions. Advance directives, although important, are just one piece of information to be used at the time of decision making.

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The traditional objective of advance care planning has been to have patients make treatment decisions in advance of serious illness so that clinicians can attempt to provide care consistent with their goals (1, 2). Advance directives and documentation of values (3–6) are the methods most often used to achieve this objective (2). Although advance directives have shown benefit in some cases (7, 8), they frequently do not affect the quality of end-of-life care or improve clinician and surrogate knowledge of patient preferences (9–13). Substantial improvements have been made in advance directives and advance care planning (6, 14–16), but many of these efforts still aim at, and are judged to be successful by, achieving the traditional objective of making advance decisions—an objective that is fundamentally flawed. On the basis of a synthesis of existing literature, we describe the problems with this traditional objective, provide an alternative objective that focuses on preparing patients and surrogates to make the best possible in-the-moment medical decisions, and outline practical steps that clinicians can take to achieve this new objective in the outpatient setting.

## PROBLEMS WITH THE TRADITIONAL OBJECTIVE OF ADVANCE CARE PLANNING

Arguments against advance decision making are well documented and are based on problems with prediction, adaptation, and extrapolation and on the nature of surrogate decision making. Individuals have difficulty predicting what they would want in future circumstances because these predictions do not reflect their current medical, emotional, or social context (17–22). In addition, patients' treatment preferences and values change when their health

changes (19, 23–25), at the end of life (26–28), and even during periods of stable health (26). One major determinant of changing preferences is adaptability. Patients often cannot envision being able to cope with disability and report the desire to forgo aggressive treatments in such states (17, 18, 29). However, once patients experience those health states, they are often more willing to accept even invasive treatments with limited benefits (27, 30–33). On the other hand, some patients may shift their goals from life prolongation to comfort (34).

Prespecifying treatment preferences or broad values statements may be appropriate for patients who can articulate consistent treatment preferences based on long-held beliefs. However, broad values statements, such as wanting to maintain dignity or be free from pain, are often too general to inform individual treatment decisions (2, 35–37). Even specific treatment preferences may be difficult to extrapolate to specific clinical situations (2, 38, 39). For example, advance directives often refer to forgoing an intervention when the patient's condition is “irreversible” or “terminal” (11). However, physicians and surrogates often have trouble determining whether patients are in these states (40). Furthermore, whereas advance directives may consider the use of only technologically intensive therapies, surrogates often face burdensome decisions about less aggressive therapies (2, 38, 41, 42), such as whether to pursue frequent hospitalizations and repeated intravenous antibiotics for aspiration pneumonia in a patient with dementia. Patients and surrogates may also need to reevaluate prespecified wishes in light of unforeseen clinical contexts (2, 13). For example, a patient's decision to forgo mechanical ventilation in the setting of lung cancer may need to be reevaluated during an episode of acute heart failure that could be successfully treated with transient ventilatory support.

In addition to the clinical context, surrogates may use their own hopes, desires, and needs to inform their decisions (13, 39, 43–45), which may contradict patients' prespecified wishes. Surrogates' consideration of additional factors beyond patients' advance treatment preferences may

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lead to better decisions and improved patient care (46). Perhaps because of an inherent understanding of the need for surrogates to base their decisions on multiple considerations, most patients want their loved ones to have leeway in decision making (4, 47–49).

### A NEW OBJECTIVE FOCUSED ON PREPARATION FOR IN-THE-MOMENT DECISION MAKING

Given the problems with prespecified treatment preferences, we propose that the main objective of advance care planning be to prepare patients and surrogates to participate with clinicians in making the best possible in-the-moment decisions. Preparing patients for such decisions shifts the focus away from premature treatment decisions based on incomplete or hypothetical information and ensures that complex health care decisions are based on a more comprehensive set of considerations, including the current clinical context, shifting and evolving goals, and patients' and surrogates' needs. These factors must be synthesized by clinicians who, depending on the patients' and surrogates' desire to be involved in decision making, can provide specific recommendations and help patients and surrogates choose from among the available alternatives (13, 14, 39, 50). This approach does not preclude the completion of an advance directive but recognizes that it is just one piece of information to be used during in-the-moment decision making (51, 52).

The complexities of in-the-moment decision making for patients with advanced illness have been well recognized and have led to efforts that focus on preparing clinicians to help patients and surrogates navigate the process (14–16, 53, 54). Furthermore, system-level constraints on end-of-life care, including bed availability and access to palliative care–trained clinicians (55, 56), have led to efforts focused on increasing the palliative care workforce and providing care options better suited to patient needs (57–59). Both clinician- and system-level changes are needed to improve care for patients with advanced illness. However, whether patients and surrogates can or should receive preparation for in-the-moment decision making in addition to these efforts is less clear. Many substantial barriers impede patients' and surrogates' meaningful participation in preparation for in-the-moment decision making.

First, it can be difficult, if not impossible, for patients and surrogates to consider all of the implications of in-the-moment treatment decisions, including the substantial logistic, financial, and caregiver burdens that may occur (56). Second, many patients and surrogates do not want to think about issues related to illness, death, and dying, and they may not want to participate in decision making (47, 60–62). Finally, clinicians do not have time for lengthy discussions on advance care planning.

Why then should efforts to prepare for in-the-moment decision making include patients and surrogates? Inclusion of these persons is not meant to shift the burdens and

complexities of medical decision making to them. Rather, clinicians cannot make high-quality in-the-moment treatment recommendations or guide patients and surrogates through the decision-making process without incorporating the patients' and surrogates' values and needs. Because these perspectives are highly individual, they can be provided only by the patient or surrogate. Given the extreme stress experienced by patients and surrogates (13) and the frequent absence of a previous relationship with the clinician at the time a decision must be made (63), patients and surrogates will likely be unable to communicate effectively without some form of preparation (2, 13).

Considering the specific challenges of in-the-moment decision making and how they contribute to stress, conflict, and decision-making burden for patients and surrogates can help to identify essential preparatory steps. Up to 76% of patients will be unable to participate in some or all of their own end-of-life decisions (8, 63–65). Surrogates who have made medical decisions for others report being unprepared (34) and describe the process as highly stressful (42, 66–68). Despite the limitations of advance statements of preference, surrogates find decision making more difficult if they do not have a sense of what the patient may have wanted, and in fact, they frequently lack this sense (34, 37, 68).

A major challenge is to help patients identify and articulate their values in a way that can guide decisions. Although it is impossible to know with certainty what a patient would have wanted, and although advance statements of preference should not be the sole consideration on which in-the-moment decisions are based, it is nonetheless possible for surrogates to use a fundamental understanding of the patients' values as one of the many considerations informing in-the-moment decisions (2, 13, 50). In contrast to eliciting preferences for specific interventions, what matters most to patients when thinking about health care decisions is the potential outcomes of treatment (33, 69–72). Therefore, asking patients to consider what outcomes they most hope for or fear can effectively identify their values in a way that can inform decision making (72–75). Asking patients to do this over time can help patients, surrogates, and clinicians recognize whether and how patients are either adapting to their illness or reaching a point where the burdens involved in fighting their illness become too great.

However, understanding patients' preferences is not enough. Surrogates may still need to make decisions that conflict with this understanding. This conflict greatly contributes to surrogate stress, especially if surrogates were not given leeway in decision making (34, 68). For example, surrogates report guilt when they cannot honor a patient's wish to die at home, generally because they cannot provide the care necessary to ensure sufficient palliation (34, 68). These experiences suggest that surrogate burden may be eased by establishing leeway in decision making before a medical crisis to address potential conflicts between pa-

**Table 1. Assessing and Addressing Lack of Readiness to Prepare for In-the-Moment End-of-Life Decision Making****Assessing readiness**

"If you were to get very sick, is there anyone you trust to make medical decisions for you, and have you talked with this person about what is important to you? Can we talk about this today?"

**Educating and motivating**

"Because of illness or an accident, most patients will be unable to make their own decisions at some time in their life."

"Because making decisions for someone is very stressful, you could help to take the burden off of your family/friends by starting to think about what would be important to you if you became very sick."

"When patients talk with me and their loved ones about what would be important to them if they were to become very sick, it helps them to keep a sense of control about their medical care and to have peace of mind."

**Addressing barriers**

"Are there things that you worry about when you think about your loved one making decisions for you?"

"Are there reasons it is difficult to talk about such things with me or your loved ones?"

tients' desires and other factors relevant during in-the-moment decision making (14, 34, 37, 68, 76).

## STEPS TO PREPARE PATIENTS AND SURROGATES FOR IN-THE-MOMENT DECISION MAKING

Three key steps address patients' and surrogates' needs for preparation for in-the-moment decision making: choosing an appropriate surrogate decision maker, clarifying and articulating patients' values over time, and establishing leeway in surrogate decision making. These steps are included in other, more comprehensive and successful advance care planning programs (6, 77, 78). However, these programs require the efforts of either a specially trained facilitator or highly motivated patients and surrogates who can engage in advance care planning on their own. Because most primary care patients want their clinicians to initiate these discussions (79, 80), clinicians will need to engage their patients for preparation to have a broad reach. To be feasible, these interactions must be brief. The efficiency of such interactions can be enhanced by assessing patients' readiness for engagement and following up with a tailored response (62). For patients who are not ready to engage in preparation, the most efficient use of the clinician's time is to educate, motivate, and address barriers to participation (81). Patients who are ready but unlikely to engage in preparation outside the clinicians' office can be guided by their clinicians through the preparatory steps over 1 or more visits. The steps also provide highly motivated patients and surrogates the chance to continue preparation on their own.

### Assessing and Addressing Patients' Lack of Readiness to Engage in Preparation

Readiness can be assessed by asking, "If you were to get very sick, is there anyone you trust to make medical

decisions for you, and have you talked with this person about what is important to you? Can we talk about this today?" Patients may respond in many ways indicating they are not ready to engage in preparation (for example, "I do not plan to get sick" or "I don't want to burden my family") (60, 62, 82, 83). Patients can be motivated to engage in preparation by appealing to the benefits of the process, including reducing surrogate burden, maintaining control, and achieving peace of mind (82–86). Clinicians

**Table 2. Steps to Prepare Patients for In-the-Moment End-of-Life Decision Making\*****Step 1: Choosing an appropriate surrogate decision maker**

Opening: "As your clinician, it would be helpful to know who to contact if you were to become really sick."

**Choosing a surrogate**

"If you were to become really sick, is there anyone you trust to make medical decisions for you?"

"Does this person know that you have chosen him/her for this role? It is important to ask him/her if he/she is willing to do it."

**Step 2: Clarifying and articulating patients' values over time**

Opening: "Patients are often deeply affected by their past medical experiences."

**Clarifying patient values**

"Have you seen someone on television/had someone close to you/had your own experience with serious illness or death?" (73)

"If you were in this situation (again), what would you hope for? What would you be most worried about?" (73, 88)

"Did this situation make you think of ways of being that would be so unacceptable that you would consider it worse than death?" (72, 73)

"Some patients say that if they became so sick that they could not recognize or talk to their loved ones (for example, if they had dementia or were in a coma), they would want all possible treatments to prolong their life. Other patients say they would rather have care focused on comfort. Which kind of person are you?"

**Exploring changes**

"Your health has changed/will change over time. Sometimes patients can get used to these changes and sometimes they cannot. In the past, you told me that (e.g., staying out of the hospital) was important to you."

"When (e.g., you were in the hospital with your heart failure, when your brother died), did this situation change your opinion about the ways of being that would be unacceptable or a state worse than death?"

"If you went through this situation again, would it be worth it to you?"

**Step 3: Establishing leeway in surrogate decision making**

Opening: "If your loved ones have to make medical decisions for you, they have to think about what you said in the past, but also about what the doctors are telling them about your medical condition and what they are able to do for you. If these differ from one another, this can be very stressful for your loved one."

**Establishing leeway**

"Having told me what is important to you, what if your surrogate finds it difficult to provide this for you?"

"What if it is too hard for loved ones to provide care for you/help you die at home?"

"What if, based on changes in your health, the doctors recommend something different from what you have told your loved one?"

"Will you give your loved one(s) permission to work with your doctors to make the best decision they can for you even if it may differ from what you said you wanted in the past?"

"Are there certain decisions about your health that you would never want your loved one to change under any circumstances?"

\* These examples can be used by clinicians to meet their own individual preferences and the individual needs of patients and surrogates. These statements and questions can and should be modified as needed.



can also address barriers to participation as an additional means of promoting readiness (Table 1) (60, 62, 81).

### Step 1: Choosing an Appropriate Surrogate Decision Maker

In this step, clinicians ask patients to identify an appropriate surrogate and try to ensure that the surrogate has been asked to play this role (Table 2). Ideally, the surrogate should accompany the patient to an appointment so that the clinician can assess his or her understanding and acceptance of the surrogate role. This can be assessed by asking, "If your loved one were to become very sick, are you willing to make medical decisions for him/her?"

### Step 2: Clarifying and Articulating Patients' Values Over Time

A useful technique to help patients articulate their values is to have them discuss how they feel about the health states experienced by themselves or others (73). Patients who have not personally been ill can reflect on stories in the media or on health care experiences of family or friends (Table 2) (73, 87). Clinicians can ask, "If you were in this situation, what would you hope for?" or "What would you be most worried about?" (73, 88). Clinicians can also ask patients whether they consider any of these health states worse than death (72, 74, 75) or whether, in such a state, they would prefer treatment to focus on comfort rather than life extension. As patients progress along their disease trajectory, these discussions can move from general considerations to specific personal experiences (for example, "When you were in the hospital with heart failure . . ." [89]) (Table 2). Clinicians can also help patients reflect on whether they are changing or adapting to serious illness, which is shown to help patients better predict their preferences (90): "You told me in the past that [for example, not being able to leave the house independently] would not be acceptable to you. Now that this has happened to you, have you changed your opinion about the ways of being that would be unacceptable?" (Table 2).

### Step 3: Establishing Leeway in Surrogate Decision Making

In this step, patients and surrogates think about factors other than patient preferences that may be relevant to in-the-moment decisions, and patients consider giving surrogates leeway in decision making (13, 39, 50). Studies of surrogate decision making suggest that 2 common scenarios should be addressed. For patients who value life extension and want to have treatment regardless of the outcome, clinicians can ask, "What if your health changes and your doctors recommend against further treatment?" For patients who want to be cared for at home, clinicians can ask, "What if it is too hard for loved ones to provide care for you/help you die at home?" It is important to include surrogates in these discussions to improve patient-surrogate understanding, to help surrogates realize whether they have permission to make decisions based on considerations other than the patient's stated preferences, and to identify

irreconcilable differences that necessitate the appointment of a different surrogate (45).

Patients who complete the preparatory steps can be encouraged to complete a durable power of attorney form and to prepare family and friends. Clinicians can say, "To avoid conflict, it is important to tell your other family and friends that you chose your loved one to make medical decisions for you/have given him/her flexibility in decision making" (13, 91). For patients who have severe illness, stable preferences, and the desire, documenting their wishes may then be appropriate (92).

## CONCLUSION

The main objective of advance care planning, rather than advance treatment decisions, should be to prepare patients and surrogates to work with their clinicians to make the best possible in-the-moment medical decisions. Clinicians can help prepare patients and surrogates in the outpatient setting to communicate their values and needs when the time comes to make a decision and to establish leeway in surrogate decision making. Future efforts will need to determine whether the preparatory steps result in increased engagement in and quality of medical decision making; whether medical treatments obtained are the result of informed decisions; and whether these decisions take into consideration the patients' goals, patients' and surrogates' needs, and the specific clinical circumstances.

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