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

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### Abstract

The traditional objective of advance care planning has been to have patients make treatment decisions in advance in an attempt to provide care consistent with their goals. We argue 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. We 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 patients and their surrogates for the types of decisions and conflicts they may encounter when they do have to engage in in-the-moment decision making. This approach does not preclude the completion of advance directives, but acknowledges that they are but one piece of information to be used at the time of decision making.

### Introduction

The traditional objective of advance care planning has been to have patients make treatment decisions in advance in an attempt to provide care consistent with their goals (1,2). Advance directives and the documentation of values (3-6), have been the method most often used to achieve this objective (2). Although advance directives have, in some cases, shown benefit (7-8), they frequently fail to affect the quality of care received at the end-of-life or improve clinicians' and surrogates' knowledge of patients' preferences (9-13). Substantial improvements have been made to advance directives and advance care planning (6,14-16). Nonetheless, many of these efforts continue to be aimed at, and/or judged to be successful by, obtaining the traditional objective of making advance decisions – an objective which is fundamentally flawed. Based on a synthesis of existing literature, the purpose of this paper is to describe the problems with the traditional objective of advance care planning; 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.

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## Problems With the Traditional Objective of Advance Care Planning

Arguments against advance decision making are well documented and based on problems with prediction, adaptation, 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 one's current medical, emotional, or social context (17-22). In addition, patients' treatment preferences and values change with changes in health (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 often 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). Conversely, some patients may shift their goals from life-prolongation to comfort (34).

Pre-specifying 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, have been found to be 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 frequently have difficulty determining when patients are in these states (40). Moreover, whereas advance directives may only consider the use of 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 re-evaluate pre-specified wishes in the 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 re-evaluated during an acute heart failure episode that could be successfully treated with transient ventilatory support.

In addition to the clinical context, surrogates may also use their own hopes, desires and needs to inform their decisions (13,39,43-45). Therefore, surrogates decisions may contradict patients' pre-specified wishes. Surrogates' consideration of factors in addition to patients' advance treatment preferences may 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, the majority of patients want their loved ones to have the leeway in decision making (4,47-49).

## A New Objective of Advance Care Planning Focused on Preparation for in-the-Moment Decision-Making

Given the problems with the pre-specification of 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. A preparation for in-the-moment decision-making approach shifts the focus away from asking patients to make what are often premature treatment decisions based on incomplete or hypothetical information. Rather, this approach seeks to ensure that complex healthcare 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 upon the patient and surrogates' desire to be involved in decision making, can provide specific recommendations and/or help patients and surrogates decide among available alternatives (13-14,39,50). This approach does not preclude the completion

of an advance directive, but recognizes that it is but 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 focused on preparing clinicians to help patients and surrogates navigate in-the-moment decisions (14-16,53-54). Furthermore, system-level constraints on the care received at the end-of-life, 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 patients' needs (57-59). Both clinician- and system-level changes are necessary to improve care for patients with advanced illness. What remains less clear, however, is whether, in addition to these efforts, patients and surrogates can and/or should receive preparation for in-the-moment decision-making. There are a number of substantial barriers to 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 that in-the-moment treatment decisions entail, including the substantial logistic, financial, and caregiver burdens that may arise (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 to have lengthy advance care planning discussions.

Why then, with all of these barriers, should efforts aimed at preparation for in-the-moment decision making include patients and surrogates? The inclusion of patients and surrogates 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 patients' and surrogates' values and needs. Because these perspectives are highly individual, they can only be provided by the patient and/or surrogate. Given the extreme stress experienced by patients and/or surrogates (13) and the frequent absence of a prior relationship with the clinician at the time a decision must be made (63), it is unlikely that patients and surrogates will be able to communicate effectively without some form of preparation (2,13).

A consideration of the specific challenges of in-the-moment decision making and how these challenges 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 decisions at the end-of-life (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 any sense of what the patient may have wanted and, in fact, 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 have a fundamental understanding of the patient's values as one of the multiple 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 healthcare decisions is the potential outcomes of treatment (33,69-72). Therefore, asking patients to consider what outcomes they most hope for or fear can be an effective means of identifying 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 adapting to their illness or reaching a point when the burdens involved in fighting their illness become too great.

However, understanding patients' preferences is not sufficient. 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 are unable to 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 prior to a medical crisis in order to address potential conflicts between patients' 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: 1) choosing an appropriate surrogate decision maker; 2) clarifying and articulating patients' values over time; and 3) 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 the majority of primary-care patients want their clinicians to initiate these discussions (79-80), for preparation to have a broad reach, clinicians will need to engage their patients. To be feasible, these interactions must be brief. The efficiency of these interactions can be enhanced by assessing patients' readiness for engagement followed by 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). For patients who are ready and unlikely to engage in preparation outside the clinicians' office, clinicians can guide them through the preparatory steps over one or more visits. The steps also provide highly motivated patients and surrogates 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 a number of ways indicating they are not ready to engage in preparation; e.g., "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 can also address barriers to participation as an additional means of promoting readiness (60,62,81). (Table 1)

### Step1: Choosing an Appropriate Surrogate Decision Maker

In this step, clinicians ask patients to identify an appropriate surrogate and also ensure that the surrogate has been asked to play this role. (Table 2) Ideally a surrogate should accompany the patient to an appointment so that clinicians can assess their understanding and acceptance of the surrogate role: "If your loved one were to become really 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 they have either personally experienced or seen others experience (73). Patients who do not have personal experiences with illness can reflect on stories presented in the media or on healthcare experiences of family or friends (73,87). (Table 2) Clinicians can ask, "If you were in this situation, what you would you hope for?" or "What would you be

most worried about (73,88)?” Clinicians can also ask patients to reflect on 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 e.g., “When you were in the hospital with heart failure... (82)” (Table 2) Clinicians can also help patients reflect on whether they are changing or adapting to serious illness – a technique shown to help patients better predict their preferences (90). “You told me in the past that (e.g., 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 patients' preferences, that may be relevant to in-the-moment decisions and patients consider providing surrogates leeway in decision making (13,39,50). Studies of surrogate decision-making suggest there are two common scenarios that should be addressed. For patients who value life extension and express a desire to undergo treatment regardless of its outcomes, clinicians can ask: “What if your health changes and your doctors recommend against further treatment?” For patients who express a desire 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, 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 necessitating the need to appoint a different surrogate (45).

Patients who complete the preparatory steps can be encouraged to complete a durable power of attorney form and prepare family/friends, e.g., “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 them 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 to prepare patients and surrogates in the outpatient setting to communicate their values and needs at the time a decision must be made 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 and whether medical treatments obtained are the result of informed choices that take into consideration the patients' goals, patients' and surrogates' needs, and the specific clinical circumstances.

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**Table 1**  
**Assessing and Addressing Lack of Readiness to Engage in Preparation for in-the-Moment Decision Making**

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**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 were to become 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?”

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Table 2

**Steps to Prepare Patients for in-the-Moment 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 that you trust to make medical decisions for you?

Does this person know that you have chosen them for this role? It is important to ask them if they are 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 Patients' 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 you 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/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 you were (e.g., 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?

\* This table includes a broad range of example statements/questions that clinicians can use in order to meet the individual preferences of the clinician and the individual needs of patients and surrogates. These statements/questions can and should be modified as needed.