

*Original Article*

# Advance Care Planning Beyond Advance Directives: Perspectives From Patients and Surrogates

Ryan D. McMahan, BS, BA, Sara J. Knight, PhD, Terri R. Fried, MD, and Rebecca L. Sudore, MD

*San Francisco Veterans Affairs Medical Center (R.D.M., S.J.K., R.L.S.), and Division of Geriatrics (R.D.M., R.L.S.), and Departments of Psychiatry and Urology (S.J.K.), University of California, San Francisco, San Francisco, California; Health Services Research and Development Service (S.J.K.), Veterans Health Administration, Washington, DC; and Veterans Affairs Connecticut Healthcare System and Yale University School of Medicine (T.R.F.), New Haven, Connecticut, USA*

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## Abstract

**Context.** Advance care planning (ACP) has focused on documenting life-sustaining treatment preferences in advance directives (ADs). The ADs alone may be insufficient to prepare diverse patients and surrogates for complex medical decisions.

**Objectives.** To understand what steps best prepare patients and surrogates for decision making.

**Methods.** We conducted 13 English/Spanish focus groups with participants from a Veterans Affairs and county hospital and the community. Seven groups included patients ( $n = 38$ ), aged  $\geq 65$  years, who reported making serious medical decisions. Six separate groups included surrogates ( $n = 31$ ), aged  $\geq 18$  years, who made decisions for others. Semistructured focus groups asked what activities best prepared the participants for decision making. Two investigators independently coded data and performed thematic content analysis. Disputes were resolved by consensus.

**Results.** The mean  $\pm$  SD patient age was  $78 \pm 8$  years, and 61% were nonwhite. The mean  $\pm$  SD surrogate age was  $57 \pm 10$  years, and 91% were nonwhite. Qualitative analysis identified four overarching themes about how to best prepare for decision making: 1) identify values based on past experiences and quality of life, 2) choose surrogates wisely and verify that they understand their role, 3) decide whether to grant leeway in surrogate decision making, and 4) inform other family and friends of one's wishes to prevent conflict.

**Conclusion.** Beyond ADs, patients and surrogates recommend several additional steps to prepare for medical decision making including using past experiences to identify values, verifying that the surrogate understands their role, deciding whether to grant surrogates leeway, and informing other family and friends of one's wishes. Future ACP interventions should consider incorporating

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*Address correspondence to:* Rebecca L. Sudore, MD, Division of Geriatrics, San Francisco Veterans Affairs Medical Center, University of California, San Francisco,

4150 Clement Street, #151R, San Francisco, CA 94121, USA. E-mail: [rebecca.sudore@ucsf.edu](mailto:rebecca.sudore@ucsf.edu)

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### **Key Words**

*Advance directives, decision making, aging, qualitative research*

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## **Introduction**

Because the population is aging and the prevalence of chronic disease is increasing, many older adults and their surrogate decision makers will face complex medical decisions over the course of serious and chronic illness.<sup>1,2</sup> Yet, decision making is often stressful for both patients and surrogates, and many feel unprepared to make informed choices.<sup>3–9</sup>

Preparation for medical decision making is often called advance care planning (ACP), a process traditionally focused on the documentation of preferences for a surrogate and life-prolonging procedures (e.g., mechanical ventilation) in an advance directive (AD). However, AD forms are often difficult for patients to understand, and the evidence for their clinical effectiveness has been mixed.<sup>5,10–16</sup> Furthermore, the completion of ADs alone has not been shown to decrease the stress of surrogate decision making, prevent conflict, or prepare patients to identify and communicate their values to surrogates and clinicians.<sup>17–20</sup>

ACP has begun to be considered as a series of behaviors and not just the completion of an AD.<sup>21–23</sup> Although choosing a surrogate and clarifying one's values for medical care are well-accepted additional ACP behaviors,<sup>5,22,24,25</sup> these are complex tasks involving multiple decisions over time that patients and surrogates often do not know how to accomplish.<sup>26,27</sup> Prior work has begun to explore the ways patients make medical decisions (e.g., based on outcomes of treatment and changing health),<sup>28,29</sup> about surrogates' experiences (e.g., decisions based on their own hopes),<sup>30</sup> and surrogates' challenges (e.g., making unforeseen decisions).<sup>6,30</sup> However, a concrete understanding of the specific set of tasks that can be recommended to diverse patients and their surrogates to best prepare for these complex and longitudinal medical decisions is lacking. A roadmap for *how* to prepare for decision making from patients' and surrogates' perspectives is needed. The purpose of this study was to

explore what best prepared patients and surrogates from diverse racial/ethnic backgrounds to make medical decisions for serious or complex illness and to delineate the specific concrete steps to accomplish these ACP activities.

## **Methods**

### *Setting and Recruitment*

We recruited patients and surrogates through study fliers and convenience sampling, from primary care clinics at San Francisco General Hospital and the San Francisco Veterans Affairs Medical Center and from cancer support groups and senior centers. Participants were screened for eligibility if they contacted study staff by phone or in person. In the primary care clinics, physicians were asked to approve the contact of their patients and exclude individuals determined to be too physically/cognitively impaired to participate. Patients were included if they were aged 65 years or older, had a primary care physician, and had serious or chronic illness (e.g., heart failure, coronary artery disease, chronic obstructive pulmonary disease, diabetes, or cancer) identified by chart review (from clinics) or self-report (from the community). During eligibility screening, patients were included if they reported having made serious medical decisions for themselves that involved life-prolonging treatment, such as mechanical ventilation, care in an intensive care unit, major surgery, or chemotherapy.

Surrogates were eligible if they were aged 18 years or older and reported having made serious medical decisions for someone else. Patients and surrogates were excluded if they did not speak English or Spanish, were deaf or blind, did not possess a telephone, or had moderately impaired cognition (score of <19/50) on the Telephone Interview Cognitive Status questionnaire.<sup>31</sup>

During telephone or in-person eligibility screening before focus groups, we also collected participant age, gender, race/ethnicity, self-reported health status (fair to poor vs. good,

very good, and excellent),<sup>32</sup> and self-reported limited health literacy defined as a lack of confidence filling out medical forms (not at all confident, a little, or somewhat confident vs. confident to very confident).<sup>33</sup> This study was approved by the Institutional Review Boards at the University of California, San Francisco and the San Francisco Veterans Affairs Medical Center. All participants were consented.

### *Procedures*

We conducted focus groups of mixed race/ethnicity to elicit diverse opinions and homogeneous race/ethnicity groups to encourage discussion of culturally based experiences. We continued recruitment until content saturation was achieved.<sup>34</sup> This resulted in seven patient-only focus groups (four mixed race/ethnicity groups and three Latino groups) and six surrogate-only focus groups (two mixed race/ethnicity, two African American, and two Asian/Pacific Islander groups). A mean  $\pm$  SD of  $5 \pm 2$  persons participated in each patient group and  $6 \pm 2$  persons in surrogate groups.

Based on prior work and input from experts in geriatrics, decision making, and ACP,<sup>23</sup> a semi-structured focus group outline was developed (Table 1). Focus groups were conducted by two moderators with extensive knowledge of decision making and end-of-life care (R. L. S. and/or S. J. K.). The Spanish-speaking groups were moderated by a native Spanish-speaking moderator. Three topics were discussed: 1) experiences with medical decision making and advice about how best to prepare, 2) experiences with discussions about death and advice about how best to prepare, and 3) opinions about what one should do if faced with a serious medical illness as described in a vignette (Table 1). For each topic, we specifically asked participants about the “advice” they would give others. Although separate focus groups were conducted for patients and surrogates, most participants discussed decision making from the perspective of making decisions both on behalf of oneself and on behalf of others.

### *Data Analysis*

All focus groups were audio recorded and professionally transcribed verbatim. We used a stepwise, iterative framework analysis approach, which includes becoming familiar with transcript data, developing a codebook,

indexing/coding all transcripts, and synthesizing codes into overarching themes by comparisons within and across transcripts.<sup>35</sup> Two authors were present for all groups (R. D. M. and R. L. S.) and developed an initial coding scheme from our prior work and focus group outline.<sup>23</sup> These authors then read and coded each transcript independently using NVIVO 8® software (QSR International, Burlington, MA). Through an iterative process and the use of thematic content analysis,<sup>34</sup> the first two focus group transcripts led to further development of the coding scheme. Using the constant comparative method,<sup>36</sup> the coding scheme was refined through serial review of transcripts. Overarching themes were then identified. Disagreements were resolved by consensus. Multiple steps were taken to ensure trustworthiness of our methods, including use of clear inclusion/exclusion criteria, standard focus group outline, a systematic framework analysis approach, an audit trail for coding, and by demonstrating an interrater reliability of 84%, similar to other studies.<sup>8,29,37</sup>

Because analysis revealed that patients and surrogates described preparation for decision making from both perspectives, we combined patient and surrogate focus group data in the final analysis. Frequencies or means were calculated for participant characteristics. To quantify the frequency with which themes were discussed, we determined the lines of text dedicated to a theme and the percent of participants, overall and by participants in patient and surrogate groups, who discussed a particular theme. Given the qualitative nature of this article and limited sample size, stratification of our results by participant subgroup was not conducted.

## **Results**

We enrolled 38 patients and 31 surrogates. The mean  $\pm$  SD patient age was  $78 \pm 8$  years, and 61% self-identified as nonwhite (Table 2). The mean  $\pm$  SD surrogate age was  $57 \pm 10$  years, and 91% self-identified as nonwhite.

Qualitative analyses identified a central overarching concept that ADs alone are not sufficient to fully prepare patients and surrogates for complex medical decision making. We also identified four primary themes that help to describe how to accomplish specific

*Table 1*  
**Focus Group Outline and Probing Questions**

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1. Past experiences with medical decision making	<p>Think about a time that you had to make an important or significant medical decision about serious illness.</p> <ol style="list-style-type: none"> <li>a. Who was involved in the decision?</li> <li>b. What did you realize was important to you when making this decision?</li> <li>c. How did it change the way you make other medical decisions?</li> <li>d. What might you do differently in the future?</li> <li>e. What advice would you give other people?</li> </ol> <p>What things did you do in advance, meaning before you had to make the decision, which you think would help other people make difficult decisions?</p> <ol style="list-style-type: none"> <li>a. Why do you think these things helped or did not help?</li> <li>b. Knowing what you know now, what things do you wish you (the patient or surrogate) would have done or talked about in advance that could have made the decision easier?</li> <li>c. If you were going to give advice to other patients and their families, how would you tell other patients and their families to prepare for difficult decisions?</li> </ol>
2. Past experiences with death and dying	<p>Have you ever talked with someone else about death and dying and making difficult decisions? When did this come up?</p> <ol style="list-style-type: none"> <li>a. Are there situations that triggered these discussions?</li> <li>b. Are there times or places that made talking easier or harder?</li> <li>c. When you had these discussions, what did you talk about?</li> <li>d. What advice would you give other people?</li> </ol>
3. Vignettes of serious illness	<p>A woman's husband died last year in the ICU.</p> <ol style="list-style-type: none"> <li>a. What should this woman ask herself or think about when trying to prepare to make medical decisions for herself?</li> <li>b. With your experience, what advice would you give this woman?</li> <li>c. What advice would you give other people?</li> </ol> <p>A father's advance directive states he wants "all treatments possible." The daughter is afraid she may not be able to honor these wishes.</p> <ol style="list-style-type: none"> <li>a. What do you think about this situation?</li> <li>b. Do you think this happens in real life?</li> <li>c. What would you do if this were your daughter?</li> <li>d. What do you think the daughter should do?</li> <li>e. What do you think this father and daughter should talk about to prepare?</li> <li>f. What advice would you give other people?</li> </ol> <p>A mother says she wants to die at home. The daughter is afraid she may not be able to honor these wishes.</p> <ol style="list-style-type: none"> <li>a. What do you think about this situation?</li> <li>b. Do you think this happens in real life?</li> <li>c. What would you do if this were your daughter?</li> <li>d. How would you feel if you were the daughter?</li> <li>e. What do you think the daughter should do?</li> <li>f. What do you think this mother and daughter should talk about to prepare?</li> <li>g. What advice would you give other people?</li> </ol> <p>A man's cancer has spread. Initially, he wanted to try to live as long as possible and have chemotherapy. The cancer was not cured. He began asking himself if would be worth it to go through chemotherapy again.</p> <ol style="list-style-type: none"> <li>a. What do you think about this situation?</li> <li>b. What should this person be thinking about to make the decision?</li> <li>c. With your experience, what advice would you give this person?</li> <li>d. What advice would you give other people?</li> </ol> <p>A woman calls a family meeting to tell them about her medical wishes and about her surrogate decision maker.</p> <ol style="list-style-type: none"> <li>a. What do you think about this situation?</li> <li>b. Do you think this was a good idea? Why or why not?</li> <li>c. With your experience, what advice would you give this person?</li> <li>d. What advice would you give other people?</li> </ol>

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ICU = intensive care unit.

preparatory activities beyond ADs: 1) identify values based on past experiences and individual definitions of quality of life, 2) choose surrogates wisely and verify that they understand their role, 3) consider whether to grant surrogates leeway in decision making, and 4) inform other family and friends about one's wishes.

These themes were discussed frequently by both patients and surrogates (Table 3).

#### *Use of ADs Alone Is Not Sufficient*

A central overarching concept was that ADs do not always help during real-life medical decision making or when faced with myriad

Table 2  
Participant Characteristics

Characteristics	Patients, N= 38	Surrogates, N= 31
	n (%)	n (%)
Age		
Mean yrs $\pm$ SD (range)	78 $\pm$ 8 (65–89)	57 $\pm$ 10 (33–76)
Gender		
Female	12 (32)	21 (68)
Race/ethnicity		
White, non-Hispanic	15 (39)	3 (9)
African American	4 (11)	16 (52)
Latino/Hispanic	13 (34)	0 (0)
Asian/Pacific Islander	6 (16)	12 (39)
Fair-to-poor health status	16 (42)	9 (29)
Limited health literacy	10 (26)	5 (16)

unforeseen circumstances. For instance, many participants described the inadequacies of ADs saying that the “hypothetical situations” often used in ADs did not prepare them to face the uncertainty of “real” complex medical decision making (Table 4).

Most participants also stated that focusing on specific treatment preferences, such as “the DNR” (Do Not Resuscitate), was not enough to help make the “many decisions” with which they were faced, stating, “The other stuff we were guessing at ...” (Table 4). Some of the additional decisions discussed included whether to have surgery, transition to hospice, or be cared for in the home or nursing home.

### Identifying Values Based on Past Experiences and Quality of Life

One of the main preparatory themes identified by participants was the use of past experiences, “worst-case scenarios,” and focusing on “quality of life” as a means to clarify one’s life

goals and values for medical care (Table 4). To clarify current preferences for medical care, participants identified past experiences with personal illness or with loved ones who were sick or dying as powerful tools. For example, a near-death experience changed one participant’s preferences, “It was like dreaming. I told myself afterwards that death is not such a bad thing.” Another man who had watched his father die of pancreatic cancer decided he would choose a comfort care approach for his own care because he said, “I don’t want to put my family through it” (i.e., prolonged death of a loved one on life support). Another participant decided that he would choose hospice because he witnessed his wife, who “went very peacefully” with hospice care.

Participants also found the identification of worst-case scenarios as a good way to identify overall preferences for care. One surrogate described how his father put in writing to “do everything you can to keep me alive.” After his father documented these wishes, his son spoke to him about worst-case scenarios and found that “he did not want to have any life-saving efforts” in those situations (Table 4). Participants described how worst-case scenario information could help the surrogate and physician make medical decisions if that scenario occurred.

Participants also identified individual definitions of quality of life and taking the “big picture” into account as central to making decisions about medical care. Subjects spoke of the need to focus not just only on medical treatment but also on the quality of life “before that” (before treatment was offered) and “afterward.” Participants also discussed that “The quality of life to one person is one thing and to another person it’s another thing and that ought to be part of this advance directive”

Table 3  
Frequency With Which Themes Were Discussed

Overarching Themes	All Participants, <sup>a</sup> N= 69	Patients, <sup>b</sup> N= 38	Surrogates, <sup>b</sup> N= 31	Lines of Text Dedicated to Theme, N= 8939
	n (%)	n (%)	n (%)	n (%)
Advance directives are not sufficient	34 (49.3)	11 (29.0)	23 (74.2)	1143 (12.8)
Values clarification	61 (88.4)	35 (92.1)	26 (83.9)	2767 (31.0)
Surrogate decision makers	43 (62.3)	28 (73.7)	27 (87.1)	1098 (12.2)
Leeway in decision making	55 (79.7)	28 (73.7)	27 (87.1)	1254 (14.0)
Informing family/friends of wishes	60 (87.0)	33 (86.8)	27 (87.1)	1973 (22.1)

<sup>a</sup>Percentage of all participants (both patients and surrogates) who discussed a particular theme.

<sup>b</sup>Percentage of individuals who initially self-identified as a patient in patients focus groups and as a surrogate in surrogate focus groups who discussed a particular theme.

Table 4  
Additional Advance Care Planning Steps to Prepare for Medical Decision Making

Theme	Quote
<b>Use of advance directives alone is not sufficient</b>	
Hypothetical scenarios	"It's one thing for somebody to say, 'Oh, yeah, treat me, give me everything known to mankind, you know,' but the family still is now faced with a situation that, you know, was only theoretical before, but now it's for real."
Many decisions to be made	"The only thing that I managed to talk to my father about was asking about DNR—that if anything should happen and his heart should stop or whatever ... That was the extent of how much I knew what his wishes were. The other stuff we were guessing at as to, you know, whether he would want being home or in a hospice or whatever."
<b>Identifying values based on past experiences and quality of life</b>	
Use past experiences	"My father, he had cancer of the bile duct and he went through surgery and just suffered incredibly and he died a miserable death and he was suffering for about six months in a hospital—I watched that process so I decided I don't want to put myself through it and I don't want to put my family through it."
Consider worst-case scenarios	"My father-in-law had diabetes and his will was that you do everything you can to keep me alive, cut off his legs and all this kind of stuff and he still wanted to live. But then my wife finally asked him. She said, 'What do you want me to do if it comes to worse than that? You know, you can have a stroke and go into a coma. Do you want us to continue'—and he said, well, if the worst case situation comes up, then he didn't want to have any life-saving efforts. So I would ask that maybe the family should present to that person the worst case scenario."
Focus on quality of life	"I would evaluate in terms of, well, quality of life. I think that every situation is different and I think that drugs can only do so much; the equipment can only go so far and our body can only sustain so much, so when you come to that point of, you know, if your body gives out, should you resuscitate, it depends on the situation, you know, what is the quality of life afterwards. What was the quality of life before that?"
Based on individual definitions of quality of life	"We're a generation of people that like to take care of ourselves and we don't want anybody else to tell us anything. I have daughters and I said, 'Look, I don't want all these tubes. I don't want nobody turning me. I don't want a feeding tube. I like eating.' So to wake up and realize I have a feeding tube or I have a breathing tube, I wouldn't be happy, you know. When it's time for me to decline, lord, just let me go. I don't want to wake up somebody saying, 'Keep her.' Keep me for what? If I can't get up and do for myself, I don't want to be here." "See, I would like to live till I was 200. Can't think any more, can't do nothing anymore because I love life and I love what's out there. The older I get, the more determined I am. I still want to live."
Reevaluate over time	"And I think an advance directive, if you make it very early, you may say you want this in your 30s or 40s or your 20s, but you get to your 50s—You don't feel the same way. You may have a different perspective out of life. You may have things that have happened. Maybe you realize how really precious life really is. You get to your 60s, then you see people that are unable to get up, unable to eat, unable to move. You may change your mind again about it. So just like insurance policies and leases need to be updated, so should an advance directive."
<b>Choosing a surrogate and verifying their understanding</b>	
Choose based on ability	"I don't want my daughter making any decisions. She likes to do things the way she wants them done. My grandson will do what I ask him to do." "The black community is always the oldest (child). That does not mean they are the smartest. It's important to know why is that person choosing that person." "I'm going to have to find somebody outside my four daughters. One of my daughters has an anxiety attack and I'm seeing how they was responding and I'm like, 'Oh, no, I can't have them in charge of my life.' They're aware and they know that."
May change over time	"When you write, 'I trust this person' maybe years ago. You may give it to your nice daughter, and she may marry somebody who's a religious fanatic or, at the last minute, you change religion. Things change."
Need to prepare surrogate	"Well one thing that would be important to me to emphasize how inconvenient it would be if a family member who leaves no way of knowing what to do if he or she is too sick to speak for himself. For instance, if somebody is in a coma ... Well, you can't just say, 'Well, we'll pull the plug,' because the guy didn't tell us we're supposed to pull the plug. What are we going to do now? It would be important for the sake of the people you're leaving behind and considerate of them to let them know that this is (what you) want and not leave them out."
<b>Considering whether to grant surrogates leeway</b>	
Patients want to grant leeway	"Yeah, I think if I were asked how come I don't do an advance directive I think it's because I trust that my wife could make a good decision. I mean, the problem with doing an advance directive is it does take it out of their hands which is also not good because they should be able have a say in what happens to me."

(Continued)

Table 4  
Continued

Theme	Quote
Allows surrogate to be an advocate	"And the thing with the advance directives too is that they can change at any time. But, somebody needs to be close enough to you as to say that, 'No, she changed her mind about that. So, I don't think that's what she wants.'"
Allow surrogate to make best in-the-moment decision	"And as the executrix for my grandmother, then whatever was the best possible care at that moment, assessing that, you know, consulting with the physicians to say whether or not, you know, the breathing tube, there is a percent, you know, chance. It would be helpful (to know) if it's not going to do any good. So in that moment, you're making decisions."
Leeway not always prudent	"If you have a lot of confidence in the other person to have your best interests at heart, it would be O.K., but that may not always be the case, even with a relative. I've had some experience like that with a family member who passed. Some of his immediate kin disagreed with his wishes and they changed it a little bit and I don't think that was right. But, if the person's intentions towards you are excellent and you're sure of them, it's O.K."
<b>Informing family and friends about one's wishes</b>	
To prevent conflict	"My father-in-law passed away and my wife is the oldest of five girls. I'll tell you the personal things came out after he passed which we didn't know existed ... It ended up in a lawsuit because they said, you know, 'You decided this and, you know, dad didn't tell us that they wanted this.' When, in fact, he told my wife, 'So the best thing I think they should do, they should talk to the whole family and say, 'This is what mom and dad wants' before he passes on.'"
Provide control for the patient	"I say call a meeting and you force everybody to come to the table and talk. That way if you have any questions, ask me because it's about me and so don't go to my son or anyone else and have a complaint about 'Oh, she chose so and so and so and so.' You've got something to say, tell me because this is what I want and this is my last say."
Provide control for surrogate	"My dad called a meeting and he said that I would be the decision-maker over his medical decision(s) and my sister would be the decision-maker over his financial. My other siblings got mad. But that was the bottom line. It was over. It was said. Everybody knew and when my sister and I made those decisions, they all got back. I thought that was the bravest thing that I have ever seen when he made the meeting. They all knew to get out of our way."

(Table 4). Preferences for medical care were discussed in the context of firmly held beliefs and what was most important in life, such as religion, not wanting to burden family, remaining independent, or "loving life" and focusing on longevity.

Participants discussed how over time "you may have a different perspective," and how individual definitions of quality of life will change. Participants recommended reevaluating individual definitions of quality of life based on new life circumstances and changes in health on a regular basis, "just like insurance policies need to be updated."

#### *Choosing Surrogates and Verifying Their Understanding*

Another main theme included how best to identify and prepare the surrogate. Several participants discussed the need to seriously consider choosing someone who can be trusted to make sound decisions, is emotionally stable,

able to ask doctors questions during a crisis, and available when needed (Table 4). Many spoke about how the best surrogate may not be the next-of-kin. One man said, "My wife wouldn't be objective. She'd be too wrought-up in the moment, whereas my daughter, I think, would make a good judgment."

Participants also discussed the need to evaluate how an individual would make decisions for another person and to be realistic about the surrogate's abilities. One person said that her sister would only make decisions based on "the way she wants them done ..." and another spoke about how her extended family would make decisions based on greed, "They just want to pick over my things. They don't care." Some spoke about the practical need to choose someone who lives close and would have time to help (Table 4). One woman spoke about how her daughters were busy with their own children, whereas her son had not yet married. She said, "You have to face the truth" about what potential

surrogates are able to do based on their own life circumstances. In addition, several people discussed the need to reassess or change a surrogate over time if the surrogate dies, moves, or if situations or one's relationship changes.

Many participants discussed the need to verify that the surrogate knows and agrees to the role. Several surrogates described how surprised they were at being selected to make medical decisions. One woman noted that "he (her father-in-law) surprised me" by designating her as his surrogate. Another woman said, "I didn't know I was going to be put in that position," to make medical decisions for her ex-husband. Participants recommended talking to the surrogate ahead of time so that the surrogate can agree or disagree. One man spoke of the importance of talking to and preparing the surrogate ahead of time to decrease burden by saying it was "... for the sake of the people you're leaving behind to let them know that this is [what you] want and not leave them out."

#### *Considering Whether to Grant Surrogates Leeway in Decision Making*

Participants also discussed granting leeway or flexibility for a surrogate to make decisions in the light of unforeseen circumstances based on factors other than, or in addition to, the patient's prior stated wishes. Despite participants reporting strongly held opinions about their quality of life, they also recognized the difficulty of applying these preferences to specific situations and the need to take other factors into account at the time decisions need to be made. For instance, both patients and surrogates spoke about the inherent uncertainty of medical decision making with changing health. In this context, many participants described wanting to grant leeway to their surrogate because they trusted their judgment (Table 4). One participant spoke about how an AD that included specific treatment preferences would "take it out of [his wife's and daughter's] hands" even if they were designated surrogates. This participant saw the loss of potential decision-making authority for his wife and daughter as "not good because they should have a say in what happens to me."

Leeway also was discussed as a way in which the surrogate would be empowered to act as

the best advocate during changing health situations because "[situations] can change and someone needs to be close enough to you (the patient) to say, 'No, she changed her mind.'" One woman said that having leeway and being able to work with the doctors would allow her to decide on "the best possible care at that moment" for her grandmother.

Some participants felt that granting leeway may not be prudent in all cases and that the surrogates' motives should be examined before leeway is granted. Others worried that granting leeway could place burden on the surrogate and reported mixed feelings. For instance, one woman said, "I don't want to burden my daughter to have to make the decision," but then ended the conversation by saying that she trusted her daughter to make whatever decision she thought was best at the time, even if it differed from prior decisions.

#### *Informing Family and Friends About One's Wishes*

Several participants felt that informing others about one's wishes was critical to help relieve surrogate burden and prevent conflict. Many spoke about how talking to family and friends would give both the individual and their surrogate a sense of control (Table 4). One surrogate recounted a family meeting organized by her father saying: "That was the bravest thing that I have ever seen when he called that meeting. [The siblings] all knew to get out of our way." A few participants noted that talking to some families may not prevent conflict; "No matter what you tell the family, 'I gave your mom power of attorney and she can change decisions,' there will be somebody who hates you for doing that." In these cases, some participants suggested that it could be helpful to discuss one's wishes with family or friends "one at a time" or to include discussions with an "outside person that's neutral" such as a social worker or physician.

### **Discussion**

This study adds to the literature by describing, from diverse patients' and surrogates' perspectives, which set of discrete ACP activities patients and surrogates can engage in to best prepare for complex longitudinal decisions



regarding ACP. These activities diverge from standard ADs, which often focus solely on asking patients to decide about specific medical treatment, such as mechanical ventilation, in response to hypothetical scenarios.<sup>38</sup> To prepare for multiple complex decisions, patients and surrogates stressed the importance of identifying and clarifying one's values based on evolving goals within the context of past experiences and individual definitions of quality of life; choosing surrogates wisely based on availability and ability and verifying that they understand their role; deciding about flexibility for surrogate decision making so that surrogates are empowered to adapt decisions to evolving patient needs (recognizing that leeway may not always be desired or prudent); and informing social networks broadly about one's wishes so that the surrogate's decisions are respected and conflict is avoided.

This study sheds light on the specific actions needed to define one's quality of life in a way that can inform medical decision making. These results are supported by prior studies that demonstrate that patients focus on the outcome of treatment when making decisions, such as the ability to care for themselves and their family<sup>28,29,39</sup> and that they are often highly affected by past personal or observed experiences with illness.<sup>28,30</sup> Our participants also recommended using worst-case scenarios to define medical wishes. This concept is similar to "states worse than death" that researchers have used in other studies.<sup>40,41</sup> Although the medical literature often describes patients' "goals" or "values,"<sup>42</sup> study participants repeatedly used the term quality of life and how the definition of quality will change, necessitating reevaluation over time.

Choosing a surrogate decision maker is widely accepted as one of the most important aspects of ACP.<sup>5,24,38,43</sup> Study participants expanded this concept to also include careful consideration of the surrogate based on motives and ability, such as living close and being able to ask the doctors questions. To our knowledge, only one study of young undergraduate students assessed how students would choose a surrogate based on hypothetical scenarios.<sup>44</sup> Also, building on other studies that describe how surrogates feel unprepared for decision making,<sup>5,6,45</sup> our participants recommended verifying surrogates' understanding

and willingness to accept the role and allowing them time to prepare.

A few studies and clinical vignettes have begun to discuss how allowing surrogates leeway in decision making may decrease burden on loved ones<sup>46-48</sup> and may help to prevent conflict.<sup>19,20,49</sup> However, not all patients want to grant leeway,<sup>46,48</sup> with the greatest concern, again, being a desire to prevent surrogate burden. As our participants recommend, deciding how much leeway to give and discussing the reasons behind granting leeway may go a long way in preventing conflicts that often occur when surrogates' wishes and prior ADs do not agree.<sup>20,46</sup> Finally, conflict between family members about the patient's wishes is a well-documented phenomenon.<sup>18,19</sup> Our participants recommend that individuals should inform family and friends early on of one's wishes to prevent conflict.

Several considerations are important in the interpretation of our findings. Participants were from one geographic location in northern California, limiting the generalizability of our results.<sup>50</sup> Furthermore, approximately half of the participants contacted study staff in response to flyers, potentially resulting in selection bias. In addition, we may have found different results based on culture had we conducted an equal number of diverse focus groups (e.g., Latino) in both dedicated patient and surrogate focus groups. However, most participants discussed experiences from both a patient and surrogate perspective. Finally, some participants were recruited from cancer support groups, which may have resulted in individuals who had thought about ACP more than the average person. However, these individuals had considerable experience making decisions for themselves and others, which we believe strengthened our findings.

This study offers several practical implications for clinicians. First, specific ACP activities, beyond ADs, may better prepare patients and surrogates for the many complex and longitudinal decisions that are often needed over the course of serious and chronic illness and close to the end of life. Second, the ACP paradigm needs to expand beyond asking patients to make premature decisions about life-prolonging procedures to also include preparation for medical decision making. Third, patients and surrogates in this study suggest

that ACP also may include these practical steps: identify values based on past experiences and individual definitions of quality of life, choose surrogates wisely and verify that they understand their role, consider whether to grant surrogates leeway, and inform other family and friends about one's wishes to prevent conflict. Future studies are needed to determine whether the incorporation of these additional steps in ACP can change care at the bedside.

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