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# Surrogate Decision Makers Need Better Preparation for Their Role: Advice from Experienced Surrogates

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## Abstract

**Background:** Surrogate decision makers are required to make difficult end-of-life decisions with little preparation. Little is known about what surrogates may need to adequately prepare for their role, and few resources exist to prepare them.

**Objective:** To explore experiences and advice from surrogates about how best to prepare for the surrogate role.

**Design:** Semistructured focus groups.

**Setting/Participants:** Sixty-nine participants were recruited through convenience sampling in San Francisco area hospitals, cancer support groups, and community centers for 13 focus groups. Surrogates were included if they were 18 years of age or older and reported having made medical decisions for others.

**Measurements:** Qualitative thematic content analysis.

**Results:** Forty participants reported making surrogate decisions for others: 6 were Spanish speaking, 22 were women, 16 were Black American, 11 Asian/Pacific Islander, 6 Latinx, and 7 White; 9 had limited health literacy. The majority (29, 73%) emphasized the importance of advance care planning (ACP) and expressed the desire for additional guidance. Five themes and advice were identified: (1) lack of, but needing, surrogates' own preparation and guidance (2) initiate ACP conversations, (3) learn patient's values and preferences, (4) communicate with clinicians and advocate for patients, and (5) make informed surrogate decisions.

**Conclusion:** Experienced surrogate decision makers emphasized the importance of ACP and advised that surrogates need their own preparation to initiate ACP conversations, learn patients' values, advocate for patients, and make informed surrogate decisions. Future interventions should address these preparation topics to ease surrogate burden and decrease disparities in surrogate decision making.

**Keywords:** advance care planning; medical decision making; proxy; qualitative; serious illness

## Introduction

WHEN INDIVIDUALS LOSE THE CAPACITY to make decisions about their own medical care, such decisions regularly fall upon the patient's family members or friends. Surrogate decision making is required in up to 76% of cases at the end of life, making it a vital component of how care is delivered and how patients may experience their final stages of life.<sup>1,2</sup> However, in many cases surrogates are afforded little preparation or guidance resulting in surrogate distress.<sup>3,4</sup>

Ideally, surrogate decision making would be aided by prior advance care planning (ACP) discussions and, if appropriate, documentation of patients' wishes. ACP is a process wherein patients articulate their goals, values, and preferences for medical care.<sup>5</sup> Unfortunately, previous studies have reported that less than one in four older adults with serious illness have engaged in ACP discussions with their potential surrogate decision maker.<sup>3</sup> Consequently, less than one in four surrogates felt that they understood the patient's values and preferences regarding various health states and medical interventions.<sup>4</sup>

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Surrogates are expected to have a deep understanding of patients' preferences and values to guide complex decision making. However, studies have shown that patients prefer surrogates to respond dynamically to medical circumstances, rather than only adhere to patients' previously expressed wishes.<sup>6-8</sup> This makes surrogate decision making unique and complex as surrogates are tasked with balancing previous stated wishes, what may be known about patients' current preferences using substituted judgment, and what may be in the patient's best interest at the time of the decision.<sup>9-12</sup>

As patients' needs and contexts change, surrogates undertake many complex responsibilities, such as learning and knowing the patient's wishes, extrapolating those wishes to new circumstances and decisions, and advocating and communicating with medical providers. As a result, surrogates often report anxiety, depression, and distress, which has the potential to influence medical decisions, potentially at the cost of the patient's preferences and best interests.<sup>13,14</sup>

Although much is expected from surrogates, few ACP resources exist to prepare them for making medical decisions.<sup>15</sup> In addition, despite known health disparities in ACP, only a few prior qualitative studies of surrogates' experiences have included participants from diverse demographic backgrounds or elicited advice from experienced surrogates about how best to prepare them for their role.<sup>13,15-19</sup>

Therefore, we explored the experiences of English- and Spanish-speaking surrogate decision makers and the advice they would give to others with the goal of informing future interventions to prepare surrogates for their role.

## Methods

### Setting and participants

This is a secondary analysis of qualitative focus group data designed to explore participants' ACP experiences, as previously described.<sup>20-22</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.

Participants were recruited through fliers and convenience sampling from San Francisco hospitals, cancer support groups, and community centers. Potential participants were initially divided into two groups. The "patient" group consisted of participants aged 65 years and older who stated that they had made medical decisions for themselves. The "surrogate" group consisted of participants aged 18 years and older who stated that they had made medical decisions for others. Six groups were initially designated as "surrogate" focus groups and seven as "patient" focus groups, including three Spanish-speaking groups.

During the course of the focus groups, "patients" often spoke from the perspective of the "surrogate," as many participants had experienced both roles. Data regarding surrogate experiences were, therefore, included from both groups. Participants were excluded if they reported that they did not speak English or Spanish, were deaf or blind, did not possess a telephone, or, through screening, were found to have had moderately impaired cognition on the telephone interview cognitive status questionnaire.<sup>23</sup>

Studies have shown that disparities in ACP exist among different racial and ethnic groups, particularly with lower ACP rates among Latinx and Black American populations.<sup>24-26</sup>

Given these disparities, we asked participants about their self-identified race and ethnicity, and conducted separate focus groups for individuals who self-identified as Asian-Pacific Islander, Latinx, Black American, or White.

### Procedures

Thirteen semistructured focus groups were conducted; the focus group outline was previously published.<sup>20</sup> The topics discussed included personal experiences with medical decision making and opinions about decision making based on vignettes about serious illness.<sup>20</sup> In a unique aspect of this study, participants were asked about the "advice they would give others" in similar situations.

### Data analysis

As previously described, many individuals in the "patient" groups, organically and unprompted, discussed surrogate decision-making experiences and provided advice for other surrogates. In this study, all comments regarding surrogate decision making were included in the analysis from all 13 groups, regardless of initial group designation.<sup>20,22</sup> All groups were audio recorded, professionally transcribed, and, for Spanish-speaking groups, translated to English. Transcripts were reviewed by one author to extract quotes from surrogate perspectives for qualitative thematic content analysis.<sup>27</sup>

Two authors then independently coded all surrogate-specific data and developed a codebook. The coding scheme was then refined through serial review of the transcripts using the constant comparative method.<sup>28</sup> To ensure trustworthiness, we used a standard focus group outline and created an audit trail for coding. Overarching themes were identified, and disagreements were resolved by consensus. There is no overlap of this analysis with prior publications. However, if portions of quotes had been published in the context of unrelated research questions, we appropriately attributed the publication.

## Results

Sixty-nine participants took part in 13 focus groups (Table 1),<sup>20,21</sup> and 40 (58%) reported having made a surrogate decision. Of the 40 participants, 16 (40%) self-reported as Black American, 11 (27.5%) as Asian or Pacific Islander, 6 (15%) as Latinx or Hispanic, and 7 (17%) as White; 6 (15%) were Spanish speaking; 22 (55%) were women; and 9 (22%) had limited health literacy. Among the 40 experienced surrogate decision makers, 29 (73%) emphasized the importance of ACP and expressed the desire for additional preparation, guidance, and resources.

Five themes were identified including (1) lack of preparation and the advice that surrogates need their own preparation and guidance to (2) initiate ACP conversations, (3) learn about patient's values and preferences, (4) communicate with clinicians and advocate for patients, and (5) make informed surrogate decisions. See Table 2 for selected quotes and associated demographics. See Supplementary Table S1 for all quotes and associated demographics.

### 1. Lack of preparation and importance of ACP

Many participants described surrogacy as a role into which they or others were thrust unexpectedly or without notice: "I am on [my father's] advanced directive, DPOA

TABLE 1. CHARACTERISTICS OF FOCUS GROUP PARTICIPANTS

Characteristics	All focus group participants (n=69)	Participants with surrogate experience (n=40)
Age		
Mean, age ± SD (range)	69 ± 14 (33–89)	63 ± 13.5 (33–88)
Gender, n (%)		
Male	36 (52)	18 (45)
Female	33 (48)	22 (55)
Language, n (%)		
English speaking	56 (81)	34 (85)
Spanish speaking	13 (19)	6 (15)
Race/ethnicity, n (%)		
Asian/Pacific Islander	18 (26)	11 (27.5)
Black American	20 (29)	16 (40)
Latinx/Hispanic	13 (19)	6 (15)
White/Caucasian	18 (26)	7 (17.5)
Self-reported health status, n (%)		
Excellent to good	44 (64)	26 (65)
Fair to poor	25 (36)	14 (35)
Self-reported health literacy, n (%)		
Limited health literacy	15 (22)	9 (22.5)

SD, standard deviation.

[Durable Power of Attorney]. I never knew...he surprised me.” Examples of being thrust into the surrogate role included circumstances of acute medical crises such as a stroke or a car accident, or instances wherein there was a rapid change in the patient’s health due to a pre-existing but noncritical illness, such as sickle-cell anemia. In multiple instances participants described not being aware of their role as a surrogate until being contacted by the health care team: “I didn’t know I was going to be put in that position until the hospital called me.”

Participants emphasized the importance of ACP for surrogates, especially as it related to the difficulty of their experience. Several surrogates believed their experience would have been improved had they engaged in ACP discussions with the patient before such decisions were necessary: “What we should have done was...sit down with the family and say, ‘this is what Mom and Dad want’.”<sup>17</sup> In instances when surrogates had participated in ACP activities with the patient before making medical decisions, they reported that the surrogate role was easier to navigate: “we had it all spelled out. It made it a lot easier.”

In these cases, surrogates endorsed a clear understanding of the patient’s values and preferences for medical care and felt confident that their decisions for the patient’s care were aligned with what the patient would have wanted: “the advance directive helps [me make decisions] because everything’s in black and white.”

2. Needing guidance to initiate ACP conversations

Many surrogates described difficulty initiating ACP conversations with patients, friends, or family, with some

stating that they encountered resistance: “[My mother] didn’t want to talk about it. It’s hard when...they don’t want to open up.” Surrogates felt that they did not know how to begin ACP conversations or how to frame the conversations. This prevented them from engaging in discussions about ACP topics, “[My mother] got frustrated. She didn’t want to talk about [ACP] no more...” One surrogate who had received some guidance in conducting ACP conversations shared her advice on framing these discussions and spoke about how this approach facilitated her role as a surrogate: “We didn’t brood. We don’t talk about dying; we talk about the future.”

3. Needing guidance to learn patient’s values and preferences

Participants emphasized the importance of understanding the values and preferences of the person they would be making decisions for: “I, as a child, would feel better knowing...that I did the best I can with all the knowledge I could gather.” However, some surrogates were uncertain about how to navigate these conversations and did not know what questions to ask to understand the patient’s values and preferences for medical care: “I want to know what the framework is [for these discussions]. What do you look at first and what is the last consideration?” In some instances when surrogates had previously engaged in ACP conversations, some reported that the conversation still did not adequately prepare them for new or complex decisions that they later encountered.

In such cases, surrogates emphasized the value in engaging in these conversations to gather the information that they needed for their role, and how the lack of guidance prevented these conversations from going as well as they could have: “I managed to talk to my father about a DNR...that was the extent of how much I knew what his wishes were. The other stuff we were guessing at...or whatever.”<sup>20</sup>

Many participants also felt forced to make medical decisions without a clear understanding of what the patient would have wanted, resulting in family discord. Experienced surrogates spoke of the importance of clarifying patient’s wishes, and described how ambiguity around patients’ wishes disrupted or complicated the surrogate process: “Our mother had a [DNR] in place. We just didn’t know that, so that was difficult. [Instead, we began] making medical decisions, how to care for her at the end of her life. There may have been two of us that wanted to make Mom comfortable and then two of us to say ‘no’.”

4. Needing guidance to communicate with clinicians and advocating choices

Surrogates reported that difficulty communicating with clinical teams made it difficult to advocate on behalf of the patient. They highlighted the importance of better preparation for communication and described how a lack of communication complicated their role: “I met so many doctors that tend to just tell you [what to do] and then walk out of the room. They are very impatient.” Many surrogates emphasized the importance of advocating on behalf of the patient’s preferences, but often expressed reluctance in communicating this to the clinical team: “Somebody needs to know...to say, ‘No, I don’t think that’s what she wants’.”<sup>29</sup>

TABLE 2. SELF-REPORTED NEEDS OF CULTURALLY AND ETHNICALLY DIVERSE SURROGATE DECISION MAKERS, SELECTED QUOTES FROM TEXT

<i>Surrogate needs</i>	<i>Gender</i>	<i>Race/ethnicity</i>	<i>Age (years)</i>	<i>Surrogate quotes</i>
Lack of preparation and importance of ACP	Woman	Black American	63	"I am on that advance directive, DPOA. He did that seven years ago and I never even knew about the papers... He surprised me." (Q1)
	Woman	Black American	59	"The advance directive helps because everything's in black and white and when the person made a decision prior, they, you know, had a clear mind." (Q5)
Challenges initiating ACP conversations	Woman	Black America	58	"She [my mother] got frustrated. She didn't want to talk about it no more." (Q7)
	Woman	Asian American	61	"We didn't brood. We don't talk about dying; we talk about the future." (Q8)
Needing guidance to learn patient's values and preferences	Man	Asian American	81	"I want to know what the framework is. What do you look at first and what is the last consideration? You know, where does the family come into this and acknowledge, "Yes, let's go through with this." (Q10)
	Man	Asian American	60	"I managed to talk to my father a few years before about a DNR and he said no and, you know, that was the extent of how much I knew what his wishes were. The other stuff we were guessing at." (Q11) <sup>17</sup>
Needing guidance to communicate with clinicians and advocating choices	Man	White	80	"Having a good doctor who saw the value of counseling was important because I met so many doctors that tend to just tell you and then walk out of the room. They are very impatient." (Q13)
	Woman	Black American	58	"And the thing with advance directives is that they can change at any time. But somebody needs to know. 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'." (Q14) <sup>17</sup>
Needing guidance about how to make surrogate decisions	Man	Latinx	65	"To see [my son], his siblings, and my wife suffering, it was too hard. The decision [to remove my son's life support] was made because we couldn't do anything else" (Q17)
	Woman	Black American	71	"My husband, because of how I feel about him, I may deviate depending on what's going on at that time." (Q20)

ACP, advance care planning; DNR, do not resuscitate; DPOA, durable power of attorney.

In some cases, surrogates felt that their opinion did not align with the recommendations of the clinical team and were uncomfortable expressing this concern or felt that the best option was to default to clinician recommendations: "I wanted to try my best to keep him alive, but the doctors say 'Oh, at that age, if you put the tube in you will hurt him even more.'"

##### 5. Needing guidance about how to make informed surrogate decisions

Surrogates felt that one of the most difficult aspects of their role was navigating the decision-making process, including being asked to make a treatment decision without any additional guidance: "I had to make medical decisions for my husband. I didn't know what to do. Doctors say they need me to make a decision right now. I didn't know my answer." For some surrogates, this lack of guidance led them to default to decisions regarding treatments and therapies that prolonged the suffering of their loved ones without the understanding that alternative end-of-life options existed: "To see [my son], his siblings, and my wife suffering, it was too hard.

The decision [to remove my son's life support] was made because we couldn't do anything else." Surrogates talked about the importance of receiving guidance when navigating complicated medical decisions, describing that

they often reached out to family, friends, or clinicians for help: "My husband left the final decisions to me and I prayed on it; I spoke with people in the medical profession, my mom, nurse friends, to explain what the DNR meant. It was a very difficult decision."

In recalling their decision-making process, most surrogates who had not previously discussed ACP with the patient described using their own personal feelings about medical care or quality of life to inform their decision: "I wasn't ready to let him go, and I thought of all the ways that I could keep him alive." Even in instances when ACP discussions had taken place, some surrogates described using their own personal feelings and preferences about medical care to fill in the gaps in their direct understanding of the patient's values or preferences: "my husband, because of how I feel about him, I may deviate [from his expressed preferences] depending on what's going on at the time."

## Discussion

In this study of experienced surrogate decision makers from diverse demographic backgrounds, the majority described the importance of ACP before patients losing their decision-making capacity. This study also added to the

literature by eliciting advice from experienced surrogates about how others can best prepare for the role, specifically that preparation is needed to initiate ACP conversations with patients, to learn about patients' values and preferences, to communicate with clinicians and advocate on the patient's behalf, and to make informed surrogate decisions.

Surrogates emphasized the importance of ACP when making medical decisions.<sup>18,22</sup> Our results were similar to other studies wherein surrogates felt their knowledge of patients' preferences and values was often incomplete and inadequate.<sup>18</sup> Prior research has also demonstrated discordance between surrogates' understanding of the goals of care and the medical treatments documented in the medical record, reflecting insufficient ACP conversations before surrogacy.<sup>30</sup>

Surrogates in this study advised that the decision-making process was easier with early, substantive, and direct communication with patients regarding their values and preferences. Conversely, surrogates associated difficult decision-making processes with lack of, or low-quality, communication with patients or clinicians.<sup>13,31</sup> Indeed, prior research has validated this advice by demonstrating that higher quality communication between surrogates and patients, and between surrogates and clinicians, improves both patient and surrogate outcomes.<sup>13,31-33</sup>

Our study also highlights the complexities in how surrogates from diverse backgrounds approach medical decisions. Similar to previous studies, surrogates in our study reported using a multitude of factors when making medical decisions.<sup>10,15,18,21,34</sup> Whereas previous studies have focused on surrogate barriers, this study focused on surrogates' advice

and identified specific areas where guidance and support for surrogates have been more helpful or are most needed. The advice most often focused on the importance of communication and learning patients' wishes and goals.

Furthermore, the nuances of substituted judgment and best interests are reinforced in this study, where considerations of culture, family dynamics, and individual surrogate-patient relationships add complexity to the surrogate role.<sup>10</sup> Although the use of patients' prior wishes, substituted judgment, and best interests has historically been viewed as hierarchical, more recent guidance characterizes these components as dynamic and variably contributory based on the individual context.<sup>35-37</sup> Many of the surrogates in this study supplemented, or even substituted, the patient's expressed wishes with the surrogate's own personal experiences, family consensus, or interpretation and extrapolation of prior discussions with the patient.

This study builds on prior research by incorporating the perspectives of experienced surrogates from diverse demographic backgrounds, and also by eliciting surrogates' advice for others.<sup>19</sup> Surrogates identified themes that reflect targets for better preparation within the decision-making process, thereby illustrating specific targets for surrogate ACP interventions (Fig. 1). Interventions to prepare culturally diverse surrogate decision makers are lacking. Through the cultural adaptation process, the results of this and other studies can be used to create interventions that will meet the needs of culturally and ethnically diverse populations.<sup>13,15,19,38</sup>

There are some limitations of this study. Participant recruitment was limited to convenience sampling within a single geographic region in northern California, therefore,



FIG. 1. The self-reported preparation needs of culturally and ethnically diverse surrogate decision makers.

sampling bias is possible. In addition, the qualitative nature of this study and the size of the cohort do not allow for association of themes by individual demographics. Furthermore, the focus group format may have limited our ability to capture all contributing factors within the surrogate decision-making process.

### Conclusion

Experienced surrogate decisions makers consider ACP to be crucially important and advise that surrogates need better preparation and guidance to initiate ACP conversations with their family and friends, to learn patients' values and preferences, to communicate with medical providers and advocate on behalf of the patient, and to make informed surrogate decisions. Future research should focus on educational interventions that help surrogates prepare for their complex and unique role before an acute medical crisis to ease surrogate burden and decrease disparities in surrogate decision making.

### Author's Contributions

All persons who contributed to this study are listed as authors.

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### Author Disclosure Statement

No competing financial interests exist.

### Supplementary Material

Supplementary Table S1

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