Surviving Surrogate Decision-Making: What Helps and Hampers the Experience of Making Medical Decisions for Others

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BACKGROUND: A majority of end-of-life medical decisions are made by surrogate decision-makers who have varying degrees of preparation and comfort with their role. Having a seriously ill family member is stressful for surrogates. Moreover, most clinicians have had little training in working effectively with surrogates.

OBJECTIVES: To better understand the challenges of decision-making from the surrogate's perspective.

DESIGN: Semistructured telephone interview study of the experience of surrogate decision-making.

PARTICIPANTS: Fifty designated surrogates with previous decision-making experience.

APPROACH: We asked surrogates to describe and reflect on their experience of making medical decisions for others. After coding transcripts, we conducted a content analysis to identify and categorize factors that made decision-making more or less difficult for surrogates.

RESULTS: Surrogates identified four types of factors: (1) surrogate characteristics and life circumstances (such as coping strategies and competing responsibilities), (2) surrogates' social networks (such as intrafamily discord about the "right" decision), (3) surrogate–patient relationships and communication (such as difficulties with honoring known preferences), and (4) surrogate–clinician communication and relationship (such as interacting with a single physician whom the surrogate recognizes as the clinical spokesperson vs. many clinicians).

CONCLUSIONS: These data provide insights into the challenges that surrogates encounter when making decisions for loved ones and indicate areas where clinicians could intervene to facilitate the process of surrogate decision-making. Clinicians may want to include surrogates in advance care planning prior to decision-making, identify and address surrogate stressors during decision-making, and designate one person to communicate information about the patient's condition, prognosis, and treatment options.

KEY WORDS: surrogate decision-making; advance care planning; substituted judgment; qualitative research.
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INTRODUCTION

At the end of life, patients are often unable to make their own medical decisions. Studies have estimated that surrogate decision-makers (hereafter referred to as surrogates) make approximately 75% of decisions for hospitalized patients with life-threatening illness and 44–69% of decisions for nursing home residents.[1,2] Moreover, geriatric patients with decision-making capacity often elect to delegate decisions to their family or others.[3–6] Having seriously ill or dying family members, and making medical decisions for them, is stressful for surrogates.[7–12] In a recent study, one third of surrogates who had made medical decisions for loved ones in intensive care units (ICUs) had symptoms of posttraumatic stress disorder (PTSD).[13] Of those who had made end-of-life decisions, nearly 82% had PTSD symptoms. Conversely, care that addresses and supports both patient and family concerns (i.e., hospice care) may produce better health outcomes for surrogates. Recent studies of hospice use have identified lower mortality rates and lower rates of depression in family members of patients who had hospice care prior to death.[7,14] If clinicians are aware of the challenges that surrogates may be facing, they may be able to implement interventions to address those challenges, facilitate decision-making, and possibly preserve surrogate health.

Although they will interact with many surrogates, most Internists receive little (if any) training in how to work effectively with surrogates.[15,16] The education that many physicians-in-training receive may be limited to descriptions of the ethical principles guiding surrogate decision-making.[16] As a result, clinicians may focus primarily on the patient's needs, neglecting the surrogate's perspective and need for support as the loved one of a critically ill patient.[17] Clinicians also may find aspects of surrogate decision-making challeng-

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ing.[18] For example, they may not be sure how to respond when the surrogate's interpretation of the patient's preferences differs from what they understood from discussions with the patient, or when multiple surrogates disagree about the best care option. A first step toward addressing these challenges may be to understand what makes decision-making more or less difficult from the surrogate's perspective.

To date, most studies of surrogate decision-making have focused on how well surrogates predict their loved ones' care preferences.[19–21] The studies that have investigated the experience of surrogate decision-making have focused on the perspectives of bereaved surrogates of patients with cancer[17] and patients in ICUs.[22–25] We undertook a qualitative study to elicit surrogates' stories about their experience with making decisions for loved ones who had a variety of illnesses and who had not necessarily died. Our objective for the study was to gain an in-depth understanding of the experience and challenges of surrogate decision-making.

METHODS

Participants

Participants in this study were experienced surrogate decision-makers who were the designated surrogate decision-makers of older, chronically ill, veteran patients. These veteran patients were not enrolled in our study, but had previously participated in a separate study about advance care planning (ACP study).[26]

The recruitment methods for this study have been described previously.[27] In brief, the surrogates were recruited 2 years after completion of the ACP study. Surrogates of veterans who had been hospitalized, who had been enrolled in hospice, or who had died since the end of the ACP study received a letter (version A) describing the present study and stating that they would be contacted by telephone to discuss participation unless they requested no further contact from the study team (one surrogate made such a request). The remainder of the surrogates received a letter (version B) that described the study and asked them to call us if they had served as a surrogate decision-maker and were interested in participating.

Eligibility criteria for the surrogates included (a) being the veteran's identified surrogate decision-maker, (b) being fluent in English, (c) being able to participate in a telephone interview, (d) being free of moderate to severe cognitive impairment (as determined by fewer than five errors on the Short Portable Mental Status Questionnaire),[28,29] and (e) previous experience with surrogate decision-making (as determined by asking potential participants if they had ever made medical decisions for someone who was too ill to make their own decisions).

During the initial telephone contact, we answered questions about the study, screened for eligibility, enrolled interested and eligible participants, and obtained verbal consent for a telephone interview, which was scheduled for a later date. Of the 80 surrogates who received version A letters, 53 were eligible and 37 (70% of those eligible) enrolled in the study. All 13 surrogates who called us after receiving version B letters (out of 114 version B letters sent) were eligible and participated. We cannot calculate a response rate for the second group of surrogates because we do not know how many surrogates who received version B letters were eligible to participate.

The methods and materials related to this study were approved by the University's Institutional Review Board.

Data Collection and Analysis

After piloting the interview questions for clarity with 20 surrogate decision-makers, one investigator (EKH) conducted semistructured interviews by telephone. She asked participants to tell the story of their loved one's illness, to describe their experiences making medical decisions for others, and to reflect on what made decision-making easier and harder for them. Interviews were tape-recorded and transcribed. We continued to recruit and interview new participants until we achieved saturation of the data, the point at which additional interviews did not elicit new information.

We performed a content analysis of surrogates' reports of what made decision-making easier and harder for them.[30,31] First, we developed a coding scheme to capture the themes and concepts in the transcripts. The research team independently read three transcripts and then met to draft a coding scheme. We continued to refine the coding scheme by coding and discussing additional transcripts in team meetings until we developed consensus about the conceptual categories and the coding process. The remaining transcripts were then coded independently by two investigators from different disciplines (EKH and EKV or EKH and JST), who then met to compare their coding. To resolve discrepancies, coders discussed their rationale for coding; reread the transcripts; and, if necessary, involved a third coder to reach consensus. This helped to assure that we comprehensively coded the transcripts. To evaluate the trustworthiness of our coding process, we examined agreement by reviewing three randomly selected transcripts from each pair of coders (prior to the pairs comparing their coding): the percent agreement for one pair was 73% (range 68–75%) and 72% (range 70–75%) for the other pair. This approximates rates from other published studies.[32,33] Coded text was then entered in a qualitative analysis database (QSR N6) to facilitate analysis. We then analyzed all the passages coded as having descriptions of what helped and hampered surrogates' decision-making. We compiled a list of factors, looked for relationships between factors, created categories and subcategories of factors, and then characterized each category and subcategory.

RESULTS

Characteristics of the 50 surrogate participants are described in Table 1. The majority of participants had been involved in making end-of-life medical decisions for loved ones, including seven surrogates who had made decisions to discontinue life-sustaining treatment. Different surrogates had different responses to each type of decision. For example, making the decision to discontinue life support was highly stressful for some, but not all of the surrogates.

Surrogates identified a range of factors that contributed either positively or negatively to their decision-making, which are listed in Table 2. We have organized these factors into four categories: surrogates' characteristics and life circumstances, surrogates' social network, surrogate–patient relationship and communication, and surrogate–clinician communication and

Table 1. Surrogate Characteristics (*N*=50)

Characteristic	Value
Mean age, years (range)	63 (40–84)
Gender (% female)	90
Ethnicity (% white)	90
Education (%)	
Some high school	10
Completed high school	36
Some college	34
Completed college	20
Religious affiliation (%)	
Protestant	66
Catholic	10
Other	8
None	16
Relationship to patient (%)	
Spouse	68
Adult child	14
Other family	8
Friend	10
Mean years of relationship (range)	40 (5–76)
Type of medical decision(s) made for others (%)	
End of life	76
Surgical management	10
Medical management	14

relationship. In what follows, we describe each of these categories in more detail.

Surrogates' Characteristics and Life Circumstances

Previous surrogate decision-making experience helped some surrogates anticipate the future course of their loved ones' illness and engage in ACP. As one woman explained, "I had lost both parents of the same thing, so I had been through it before. And so I knew how to talk to him and bring up stuff that I knew that I'd been through, and so it did help a lot."

Successful coping strategies and ways of managing stress facilitated surrogate decision-making. For example, one woman appreciated her ability to "get lost" in her artwork at a time when she was making medical decisions for her dying grandmother. Other surrogates noted that decision-making was easier for them because of the support they received from their religious communities or from their own spiritual beliefs. Other strategies included anticipating life after the decision, and making the decision they would be most comfortable living with. One woman, who served as the health care agent for an elderly neighbor, reflected on making the decision to discontinue life-sustaining treatment: "I think my own strength [helped me make the decision], because to not do something that someone has asked to me would be a harder thing to live with than not doing it."

Surrogates recognized that competing responsibilities hindered their ability to make decisions for their loved ones. They described being torn between making medical decisions for loved ones and other responsibilities, such as providing care to other family members and attending to their own health issues. One woman described how she initially planned to delay surgery for a recently diagnosed breast cancer until her husband, who had a prolonged course on a ventilator after cardiac bypass surgery, was discharged from the hospital.

Surrogates described the special difficulty of making medical decisions from a distance. One woman explained how she made decisions for her husband after he was hospitalized with a stroke while in another state. This was difficult, she explained, because "I wasn't there with him to really talk to him person to person," and because she felt forced to trust the doctors assigned to her husband's case "to do what they would think best."

Finally, two surrogates described how their financial situations made decision-making harder. In both cases, difficult decisions to institutionalize elderly loved ones were made because the surrogates and their families could not afford to hire the help needed to care for their loved ones at home.

Surrogates' Social Networks

Surrogates appreciated having others to talk to about the decisions at hand including family members (especially family members trained as clinicians) and friends who were not emotionally involved in the patient's illness. Even if surrogates had been designated as their loved ones' health care agents

Table 2. Factors Affecting the Surrogate Experience of Decision-making

Helps	Hampers
Surrogates' characteristics and life circumstances	
Previous decision-making experience(s)	Competing responsibilities (i.e., aging parents)
Positive coping strategies/ managing stress	Surrogate's own health
Hobbies	Physical distance between surrogate and the patient[*]
Religious community support	Financial barriers
Spiritual beliefs	
Decision the surrogate can live with[†]	
Surrogates' social networks	
Support and others to talk to[†] (i.e., family, uninvolved friends)	Family conflict
Working towards consensus	
Surrogate–patient relationship and communication	
Responsibility, keeping a promise to the patient	Not being able to follow the patient's preferences
Decision will result in a "good" outcome (i.e., reduced patient suffering)	Emotions or attachment to the patient
Being involved—keeping up on the patient's medical condition	Weighing patient preferences against the patient's quality of life
Knowing the patient's preferences[‡]	
Surrogate–clinician communication and relationship	
Clinician availability[§]	Too many involved clinicians[‡]
Frank information from clinicians[||] (prognosis, chances of recovery, how the patient would die after withdrawal of ventilator support)	
Recommendations from clinicians	
Positive reinforcement for decision-making	
Respect from clinicians[**]	

Previous studies of surrogate decision-making also have identified these factors.

[*] Reference [34]

[†] Reference [23]

[‡] References [22, 24, 34]

[§] *References* [25, 34]

[‡] Reference [25]

[||] *References* [23, 24, 34]

[**] *References* [22, 24]

(through durable power of attorney for health care), they spoke of wanting to reach consensus about medical decisions with their families.

The presence of family conflict around the “right” decision for a loved one increased surrogate stress and made decision-making more difficult, as illustrated in the following story. One woman, who was designated as her mother’s health care agent, explained, “family’s family and when they’re dying, they want to have their say…It was a hard time…But [my brother] and I finally came to an agreement because I found some sort of a way to wait for him to come to terms with losing our mother.” She described how making the decision that she knew was the right one became easier after she realized that the opposition from her brother and other family members to her decision to discontinue ventilator support was not because they thought it was the wrong decision but because they were not ready for their loved one to die.

Surrogate–Patient Relationship and Communication

Surrogates spoke of their duty as decision-makers to do what the patient wanted and how this made their job easier. One woman described her decision to discontinue her father’s ventilator support as the last “gift” she could give him. She explained, “I had made a promise to him. It was that simple… You make that kind of commitment and you’ve got to do what you’ve got to do to see that it’s fulfilled…he was helpless, there was nothing more he could do.”

Surrogates recognized that decisions which resulted in reduced suffering or less discomfort for loved ones were easier to make. Surrogates also noted the importance of being “up on” the patient’s medical condition. This gave them a sense of being involved, but also signaled to clinicians to include them in decision-making.

Familiarity with their loved one’s preferences made decision-making easier and “took the burden” of decision-making off surrogates. One woman who had discussed “a lot of scenarios” with her husband during the course of his cancer explained, “I don’t think I could have made them [decisions] if we hadn’t discussed it.” However, she also reflected on how not being able to follow her husband’s known preferences because of logistical and clinical problems made decision-making harder: “I think the only thing that made it difficult was that I did know his wishes…to have his demise here at home, and we couldn’t do it for him. We had to make the decision to take him into the hospital so that he would be more comfortable in his last hours.”

Yet, sometimes knowing the patient’s preferences was not enough to ease the emotional difficulty of making decisions to stop treatments. One man, who was the designated health care agent for a friend, described how his love and attachment to his friend was what made the decision to discontinue life-sustaining treatment a struggle. He was aware of his friend’s care preferences and explained, “Your decision is cut and dried, but it’s a hard decision to make.”

Surrogate–Clinician Communication and Relationship

Surrogates identified aspects of their communication with clinicians that affected their ability to make decisions for loved ones. First, availability of clinicians to answer questions and offer support prior to decision-making was noted as helpful to surrogates. Second, surrogates spoke about the importance of getting frank information in lay terms that they could clearly understand from clinicians about the patient’s condition and prognosis (including the patient’s chances of recovery, how a patient’s illness would progress, or what would happen after life-support was discontinued). Receiving frank information, even if it was bad news, helped surrogates gain a broader understanding of their loved one’s illness and facilitated decision-making. Third, surrogates appreciated when clinicians made treatment recommendations. A woman who made the decision to remove her husband from ventilator support explained, “I talked to the doctors, and they all were very helpful in giving me the proper information, and telling me that he probably wouldn’t come out of it because his cancer had spread and plus he had pneumonia on top of it.” Finally, surrogates appreciated receiving reassurances from clinicians that they had made good decisions for their loved ones. They explained that this helped them get through a stressful time and get on with their lives.

When they trusted their loved ones’ clinicians, felt respected by the care team, and felt that their input was listened to and valued by the team, decisions were easier to make. An older woman who made decisions for her husband at the end of his life explained, “Dr. F. was fairly new to me, but when a doctor treats the spouse with a lot of respect and answers questions like they’re important, they give you the feeling of competence. And I think Dr. F. made me feel like a very important part of the team.”

A factor that was problematic for surrogates was having too many clinicians and no single person to coordinate communication. The wife of a patient who died shortly after an emergency surgery explained how she had responded to the situation, “There was just too many people; there were too many different stories. I was being told one thing and when another team would come through, they’d tell me something else. I was so confused during that time, I didn’t know what was going on. At that point I said, ‘I want to speak to one person and one person only. I can’t take in all this stuff.’”

DISCUSSION

These data provide insights into the challenges that surrogates face when making medical decisions for loved ones. The impact of decision-making on these surrogates was influenced by their own life circumstances, their social networks, and their relationships and communication with their ill loved ones and their clinicians. Surrogates had made different types of decisions, including decisions about medical and surgical interventions as well as end-of-life care, and had a range of responses to each type of decision. While many of these decisions were stressful for surrogates, our study was not designed to identify which surrogates might be at highest risk of increased stress based on the types of decisions at hand. An awareness of surrogates’ perspectives about decision-making for others, however, may be useful to clinicians who want to make decision-making easier for surrogates and reduce the potential for deleterious after-effects of surrogate decision-making.

Our findings are supported by previous studies and add to this literature to provide a more comprehensive list of factors that render decision-making more or less difficult for surrogates. The footnotes in Table 2 identify factors that have been noted in previous studies of surrogate decision-making. Previous studies also have documented that the burden of decision-making is lessened if surrogates (a) are aware of a patient's preferences either from conversations or advance care directives,[22,24,34] and (b) receive truthful or honest medical information from providers.[23–25,34,35] The similarities of the factors we identified to those in these previous studies increases the external validity of our findings.

These results suggest potential interventions that clinicians can use to support surrogates before, during, and after decision-making to facilitate decision-making and possibly to reduce surrogate stress and interpersonal conflict. Prior to decision-making, clinicians can include future surrogate decision-makers in ACP discussions they have with their patients. This can be done when patients are relatively stable, and before surrogates assume the decision-making role. Doing this addresses some of the surrogate-network and surrogate–patient factors, such as familiarizing surrogates and other family members with their loved ones' care preferences to prevent future family conflicts. Although surrogate familiarity with a loved one's preferences may not result in care that is more consistent with that patient's preferences, it does reduce the burden of decision-making on surrogates.[22,24,27,34,36]

During decision-making, clinicians can define the surrogate role as helping clinicians to understand what outcomes of treatment align best with the patient's goals. Rather than ask surrogates to assume the responsibility for treatment decisions, clinicians can clarify that the desired role for the surrogate's participation is to represent the patient's values and preferences, as well as the surrogates' own needs and preferences when appropriate. Clinicians can then make treatment recommendations based on their knowledge of the patient.

Clinicians also may want to identify and address surrogate stressors during decision-making. For example, clinicians may want to ask surrogates to identify the most difficult aspects of the decision at hand. After inquiring about the surrogates' support systems and other contributors to surrogates' stress, clinicians can refer them to social workers and chaplains if appropriate to discuss these issues in more depth. Referrals to palliative care teams or ethics consult services also may be helpful if the surrogate is making a decision about foregoing or withdrawing life-sustaining treatment. Finally, clinicians may need to give surrogates extra time to make a decision that they can live with.

Our results also indicate other interventions at the individual and systems level to implement during decision-making. For example, nurses can inform surrogates of hospitalized or hospice patients that they always are on duty and can contact physicians should questions arise. In addition, in-hospital teams may want to designate one physician on the primary treatment team to (a) decipher and relay medical information from involved specialists and (b) assess whether the surrogate is receiving the preferred amount of medical information.

Clinicians can help surrogates after they have made a decision. Offering reassurance that surrogates made a good decision for a loved one may help bring closure to the process and reduce the stress of continued questioning and regret related to the decision.

This study has limitations. First, the sample comprised a relatively homogenous group of mostly older, well-educated white women. Despite this, participants spoke of a wide range of decision-making experiences and identified many factors that affected their decision-making abilities. Future studies may want to address the challenges to decision-making encountered by surrogates from other ethnicities and socioeconomic groups who may approach decision-making within their family units differently.[37,38] Second, the results may be limited because participants were decision-makers for patients from one geographic area, and their decision-making experiences may be influenced by regional differences in clinician approaches to surrogate decision-making and health care system structures.[39] Third, because these were all surrogates of patients who had participated in a study about ACP, they probably had thought more about end-of-life decision-making than surrogates in the general population and may have been biased towards ACP prior to decision-making. Finally, these study interviews all took place by phone, which was selected for convenience and to allow surrogates anonymity in discussing their experiences. This method, however, restricts the analysis to the text of the interviews. Face-to-face interviews, for example, might have provided additional information about surrogates' experiences through observation of their body language and facial expressions. Ethnographic observation of surrogate–clinician interactions would have yielded additional information.

We hope these results increase clinicians' awareness of the challenges that surrogates may be facing and help them implement interventions aimed at improving surrogates' decision-making experiences. There is more to learn about surrogate decision-making, however. Future areas of investigation include examining the stress and after-effects of different types of surrogate decisions and identifying the challenges to end-of-life decision-making within families from different ethnic and cultural backgrounds. Investigators also may want to test the efficacy of interventions aimed at facilitating surrogate decision-making and decreasing the deleterious after-effects of surrogate decision-making. Until those studies are done, however, we hope that this work will benefit clinicians who interact with surrogates by helping them understand surrogates' perspectives so they can respond to individual surrogate's decision-making needs.

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