

## “Taking over somebody’s life”: Experiences of surrogate decision-makers in the surgical intensive care unit

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**Background.** Impaired capacity of patients necessitates the use of surrogates to make decisions on behalf of patients. Little is known about surrogate decision-making in the surgical intensive care unit, where the decline to critical illness is often unexpected. We sought to explore surrogate experiences with decision-making in the surgical intensive care unit.

**Methods.** This qualitative study was performed at 2 surgical intensive care units at a single, tertiary, academic hospital. Surrogate decision-makers who had made a major medical decision for a patient in the surgical intensive care unit were identified and enrolled prospectively. Semistructured telephone interviews following an interview guide were conducted within 90 days after hospitalization until thematic saturation. Recordings were transcribed, coded inductively, and analyzed utilizing an interpretive phenomenologic approach.

**Results.** A major theme that emerged from interviews (N = 19) centered on how participants perceived the surrogate role, which is best characterized by 2 archetypes: (1) Preferences Advocates, who focused on patients’ values; and (2) Clinical Facilitators, who focused on patients’ medical conditions. The primary archetype of each surrogate influenced how they defined their role and approached decisions. Preferences Advocates framed decisions in the context of patients’ values, whereas Clinical Facilitators emphasized the importance of clinical information.

**Conclusion.** The experiences of surrogates in the surgical intensive care unit are related to their understanding of what it means to be a surrogate and how they fulfill this role. Future work is needed to identify and manage the informational needs of surrogate decision-makers. (*Surgery* 2017;162:453-60.)

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WHEN A PATIENT LACKS THE CAPACITY to make decisions about medical care, the responsibility for these decisions is transferred to a surrogate. Competent patients can name their preferred surrogates before or during their hospital stay. When no surrogate has been designated for an incapacitated patient, the physician must select a surrogate, following a hierarchy of priority that varies among states. Surrogate decision-makers are involved in

71% of major medical decisions for older adults in the intensive care unit (ICU) during their first 48 hours of hospitalization.<sup>1</sup> In the substituted-judgment standard, which forms the ethical basis of surrogate decision-making, the surrogate is presumed to know the patient's values regarding health states that are acceptable or unacceptable and make health care decisions based on this knowledge.<sup>2-4</sup> In cases in which patients' values are not known, surrogates follow the best interest standard, making decisions that they feel are in the best interest of the patient. The use of surrogates is intended to preserve patient autonomy and ensure that the goals of treatment are consistent with the patient's values. However, studies have shown that surrogate decisions are frequently discordant with patient preferences.<sup>3,5,6</sup>

Qualitative studies have shown that surrogates use prior conversations of advance care planning and advance directives to inform decisions about treatment and end-of-life care.<sup>2,7-16</sup> The existing literature, however, focuses largely on nonsurgical patients with serious chronic illnesses. Patients in the surgical ICU (SICU) are unique in that surgical critical illness is often an unexpected and sudden deviation from baseline health. In contrast with the more predictable trajectory of chronic, progressive disease, long-term outcomes for SICU patients are highly variable, and prognostic estimates are sensitive to minute-by-minute changes in clinical status. Thus, the circumstances of decision-making in the SICU differ from other settings. Nonetheless, little is known about how surrogates view their role and approach decisions in the SICU.

To better align surrogates' decisions with patients' values, it is first necessary to understand the experiences and needs of surrogates. Therefore, the objective of this study was to obtain a deeper understanding of how surrogates experience decision-making in the SICU.

## METHODS

**Research theory and design.** This study sought to explore the complex social phenomenon of surrogate decision-making in the SICU using an interpretive phenomenologic approach. This research paradigm emphasizes the importance of personal recollections and attaches an interpretive dimension to analyze how informants process and make sense of their experiences.<sup>17-19</sup> The Partners Human Research Committee approved this study and waived the need for written informed consent.

**Participants and setting.** This study was performed in the general SICU and the trauma/burn SICU at Brigham and Women's Hospital, Boston, Massachusetts, USA from February through April, 2015. Based on prior studies,<sup>1,8</sup> we defined a surrogate decision-maker as a person who made a major medical decision for a family member or friend, including decisions about procedures requiring informed consent, life-sustaining treatments, or end-of-life care and post-acute placement in a nursing home or long-term acute-care hospital. Of note, this definition of surrogate decision-maker is based on the event of having made at least one major medical decision for a patient, regardless of whether they were identified as the patient's agent in a health care proxy. The objective of this study was to understand the experiences of those tasked with making decisions for a patient in the SICU. Therefore, our purposive sampling strategy considered any person who had performed this duty. Other eligibility criteria included (1) age >18 years, (2) ability to speak English, (3) ability to participate in an in-person or telephone interview, and (4) absence of moderate to severe cognitive impairment as determined by fewer than 5 errors on the Short Portable Mental Status Questionnaire.<sup>20</sup>

A researcher screened the daily SICU census and conferred with the SICU fellows and nurses to identify family members or friends of critically ill or impaired patients who had made a qualifying major medical decision and provide them with an informational letter about the study during the patient's ICU admission, with instructions for opting out of future contact. Those who did not opt out of the study were contacted by telephone 30 days after the patient was discharged or 90 days afterward if the patient had died during the admission. At that time, a member of the research team confirmed eligibility and obtained consent for an interview. Recruitment and enrollment continued until preliminary analyses revealed that thematic saturation (the point at which no new themes were identified) was achieved.<sup>21</sup>

**Research team.** The research team consisted of 3 surgeons (E.J.L., N.R.C., Z.C.), 3 anesthesiologists (J.M.L., N.S., A.M.B.), 2 intensivists (Z.C., N.S.), a nonclinician with a bachelor's degree in Human Sciences (A.B.), and a PhD-trained qualitative researcher (M.A.M.).

**Interviews.** When given the option of participating in semistructured interviews in person or by telephone, all surrogates elected for telephone interviews. An interview guide was developed for

**Table I.** Sample questions from the interview guide

<i>Domain</i>	<i>Sample questions</i>
Knowledge of role	<ul style="list-style-type: none"> <li>• In your own words, can you tell me what it means to be a surrogate?</li> <li>• How did you learn about being a surrogate decision-maker?</li> </ul>
Preparation	<ul style="list-style-type: none"> <li>• Before the surgery, did you talk to (patient) about his/her wishes for medical treatments?</li> <li>• Can you describe the circumstances of finding out your relative would need to be in the ICU?</li> </ul>
Expectations	<ul style="list-style-type: none"> <li>• What were your expectations about what the hospital course and recovery would be like after surgery?</li> <li>• What sort of decisions did you think you would need to make as a surrogate?</li> </ul>
Experience	<ul style="list-style-type: none"> <li>• Can you tell me about a specific decision you faced for (patient)?</li> <li>• What challenges or barriers did you face in making (mentioned decision) for (patient)?</li> </ul>
Confidence	<ul style="list-style-type: none"> <li>• What made you feel confident about making those decisions?</li> <li>• How comfortable do you feel in your role making decisions for (patient)?</li> </ul>
Informational needs	<ul style="list-style-type: none"> <li>• Tell me about the kinds of information that are important to you for making decisions for (patient).</li> <li>• Was there anyone at the hospital that you felt you could rely on for information and support?</li> </ul>

this study after extensive literature review and revised based on feedback from patient and family advisors (Table I). Questions explored the participant's knowledge of the surrogate role, preparation, expectations, experiences, confidence, and informational needs. E.J.L. performed all interviews following the guide and used additional probing questions driven by the interview content to encourage participants to elaborate on their experiences. Prior to the interviews, the patient's medical chart was reviewed to identify examples of decisions the participant had made, which then were used as prompts during the interviews. Interviews were recorded and transcribed verbatim. Field notes and memos were typed and analyzed alongside transcripts. Documents were compiled and managed using Atlas.ti v.7.5.10 (Scientific Software Development GmbH, Berlin, Germany).

**Analysis.** An initial set of transcripts was coded independently by members of the coding team (E.J.L., M.A.M., N.R.C., J.M.L., and A.B.) using an interpretive phenomenologic analysis approach, allowing themes to emerge from the data. The coding team then met to discuss and reconcile codes collectively for each transcript. This continued until no new codes were identified,

and a final taxonomy was developed. Each transcript was reviewed independently by a pair of coders who then compared code assignments and resolved discrepancies by consensus. Members of the research team reviewed coded data to identify relationships and major themes that emerged.

## RESULTS

During the study period, 33 surrogates were identified and provided an informational letter: 7 could not be reached, and 25 were contacted. Two of these were ineligible because they did not speak English, 1 was a court-appointed agent for an unbefriended elder and was excluded, 2 declined to be interviewed, 1 scheduled an interview initially but was subsequently lost to follow up, and 19 completed interviews. Participants were 68% female and 89% white with a mean age of 55 years (range 30–81). Prior to the hospitalization, 45% had experience as surrogates. Patients had a mean age of 65 years (range 29–96): 15 had unplanned admissions, 4 had major complications after an elective operation, and 2 died in-hospital. Six patients had good health and functional independence prior to the hospitalization, as reported by the participant. Types of decisions included consent for minor procedures (eg, central line),

**Table II.** Characteristics of participants by surrogate archetype

<i>Characteristics</i>	<i>Preference Advocates (n = 11)</i>	<i>Clinical Facilitators (n = 8)</i>
Surrogate age, y, mean (SD)	57 (12)	51 (11)
Female, <i>n</i>	7	5
White	10	7
Relationship to patient		
Spouse	5	1
Adult child	3	3
Sibling	2	3
Parent	0	1
Other relative	1	0
Friend	1	0
Designation as surrogate		
Prior to admission by patient	7	2
During admission by patient	2	4
During admission by medical team	2	2
Health care professional	2	1
Prior experience as surrogate	8	6
Prior advance care planning with patient	8	5
Patient age, y, mean (SD)	69 (13)	60 (19)
Unplanned admission	8	7
Baseline good health	4	2
Patient in-hospital death	1	1

consent for a major operation, consent for life-sustaining treatments (eg, reintubation, tracheostomy, placement of a feeding tube, code status), and long-term placement after discharge (eg, skilled nursing facilities and long-term acute-care hospitals).

Nine participants were appointed by patients in advance directives or health care proxies prior to the hospitalization, 6 were named the surrogate decision-maker by the patient after hospital admission and before loss of capacity, and 4 were chosen by the medical team, based on their close relationship to the patient, after the patient became incapacitated. When asked why they were chosen, participants cited qualifications for the role, such as a close relationship with the patient or prior health care experiences. Others described assuming the role by default in the absence of an alternative candidate. One theme from the interviews was that surrogates learned about the responsibilities of their role in real time, which one participant referred to as “on-the-job training” (wife, age 59 years). None recalled receiving instruction from clinicians on what was expected of surrogates or how to approach decisions after the patient lost capacity. As a result, they constructed their understanding of the surrogate role primarily from personal experiences and perceptions.

**Surrogate archetypes.** A major theme that emerged is best characterized by 2 dominant

surrogate archetypes, which we have termed the Preference Advocate, who focused on the patient’s values, and the Clinical Facilitator, who focused on the patient’s clinical status. Although some participants exhibited features of both archetypes, a single archetype pervaded their overall experiences. The small number of participants does not permit us to draw conclusions about characteristics associated with these archetypes. However, in this limited sample, there was no pattern of surrogate characteristics, types of decisions, or patient acuity that was solely the province of either archetype (Table II). Notably, participants with a sophisticated understanding of medicine did not assume strictly the Clinical Facilitator archetype. Likewise, familiarity with the patient’s preferences did not dictate the Preference Advocate archetype. Moreover, there was variation in participants’ personal treatment preferences and their concordance with the patients’ values. These archetypes were integral to how participants defined their role and approached decisions (Table III).

*Preference Advocate.* Participants who fit the archetype of Preference Advocate viewed the surrogate’s role as representing the patient’s values. They used their knowledge of the patient’s demeanor and prior communications about care priorities as the point of reference for considering decisions. To prepare for this role, their aim was to fully understand the patient’s values. Preference Advocates

**Table III.** Representative quotations by surrogate archetype

	<i>Preference Advocates</i>	<i>Clinical Facilitators</i>
Responsibilities of the surrogate role	It means making the decision that my father wants, ultimately. Not what I want or anyone in my family wants. It's choosing what he ultimately wants for his happiness and peace and well-being. Daughter, 34	It's just making sure that they're receiving the best care... Doing everything you can to keep that person going. Daughter, 52
Information that supports decisions	What I would say to anyone who has loved ones who are getting older is to know their wishes... We've been going on with 7 operations with my father, and if I knew about [his wishes] after the second one, I would have said, "If anything happens, so be it, because he doesn't want to be like that." Son, 46	My role was to ask questions and to get answers and to have the doctor to explain thoroughly anything that was taking place with my father regarding treatment and future treatments and future health possibilities. Son, 45
Justification for decisions	I didn't want her to suffer, and I'm not saying I wanted her to die, but if she were to come out of it and not have any kind of quality of life, I knew that wouldn't be what she wanted. Niece, 66	I did a little bit of research and found that you can live with half your small intestine, and it's not clear how many feet you have, but the minimum that I've seen was 11 feet and up to 20 feet in different references, and she only lost three feet, so she should be able to get to 100% recovery. Son, 59
Approach to discordant decisions	It means carrying out the wishes of the person that you're doing this for. As hard as it might be, I mean, luckily, my husband, he wanted something done, but if he ever said to me, "I don't want this," that would be difficult. But I'd have to carry out his wishes. Wife, 61	It's really hard in his case, when he has said in the past that he wants to die. In my head, he's sick, and he doesn't really want to die. He has children. You can't want to die when you have children—they need you. Sister, 51

who did not know the patient's health care values still emphasized the primary importance of this knowledge for fulfilling the surrogate role.

Preference Advocates framed their approach to decisions in the context of the patient's health care values. They relied on the clinical expertise of the care team and trusted them to recommend treatments that aligned with the patient's values. It was not always clear, however, whether they communicated the patient's values with all members of the care team, including surgeons and intensivists, or how they confirmed that the patient's values were considered in the recommended treatments. Instead, they gave physicians leeway to determine the most appropriate course and de-emphasized their own role in decisions. Even when prompted with specific instances, some Preference Advocates denied that these were decisions; instead, they framed the chosen treatment as the only option

consistent with the patient's values. Accordingly, they regarded informed consent as an unimportant formality.

*Clinical Facilitator.* In defining the surrogate role, Clinical Facilitators believed that their obligation was to ensure the patient received the highest quality care. To this end, Clinical Facilitators felt responsible for gaining medical knowledge, which they sought from the care team as well as from outside sources, such as the Internet or acquaintances with medical knowledge. Clinical Facilitators expanded the scope of their role beyond decision-making by engaging in the care of the patient. For example, some surrogates collected data on the patient's status by attending SICU rounds or monitoring lab values, ventilator settings, and vital signs. Clinical Facilitators described these responsibilities outside of decision-making as important contributions that surrogates make.

In contrast with Preference Advocates, Clinical Facilitators related the burden of each decision and based their decisions on clinical judgments. Although the patients' values about health care may have influenced their decisions, they were not an explicit element in their approach and process. For example, one participant recounted a conversation in which her husband stated his preference to never have a feeding tube. During his SICU admission, she refused placement of a feeding tube but provided a clinical justification—and not this prior conversation—as the major factor in her decision, stating: “In my mind, if he was on that, then it was going to take longer to get him off the vent” (wife, age 62 years). Furthermore, some Clinical Facilitators made decisions that directly contradicted the patient's values or stated preferences if they felt that the unwanted treatment was in the patient's best interest.

## DISCUSSION

Surrogate decision-makers in the SICU assume the responsibility for major decisions for surgical patients who are unable to make medical decisions for themselves. In this qualitative study, we introduce a novel construct with 2 distinct surrogate archetypes. Although all participants had been surrogate decision-makers in the SICU, their interpretation and execution of the role of the surrogate was dichotomized into 2 archetypes: an advocate for the patient's care preferences or a facilitator of the patient's clinical care. These archetypes emerged in the absence of explicit instruction on the ethical basis of the surrogate role and pervaded the lived-experience of surrogate decision-making.

To our knowledge, these archetypes have not been described in prior studies of surrogate decision-makers. Ethnographic work by Quinn et al<sup>22</sup> identified informal roles of family members in the ICU. The Clinical Facilitators archetype shares characteristics with both the roles of Primary Caregiver and Health Care Expert described by Quinn et al. Like the Primary Caregiver, Clinical Facilitators experienced angst from their lack of control over the patient's clinical care, and like the Health Care Expert, they served as a bridge between the SICU clinicians and the rest of the family. Most Clinical Facilitators in our study, however, were not medically trained nor were they caregivers for the patients prior to hospitalization. Nonetheless, they identified aspects of these roles as central to their experience as surrogates. Preference Advocates shared characteristics of the

Patient's Wishes Expert as described by Quinn et al. Although they perceived this as obligatory for fulfilling the surrogate role, not all Preference Advocates possessed knowledge of the patient's values.

Substituted judgment is the preferred standard when patients' treatment preferences are known.<sup>2-4</sup> Nonetheless, surrogate archetypes appeared to drive the approach to decision-making and, at times, presented barriers to achieving preference-concordant decisions. Clinical Facilitators justified decisions to overrule the patient's preferences if they believed that a different course of treatment was in the best interest of the patient. However, this practice opposes the principle of patient autonomy and undermines the ethical basis of surrogate decision-making. At the same time, although Preference Advocates endorsed the importance of the patient's values and priorities for decision-making, it is not clear when and how they make these values and priorities known to the clinical team. Rather, they presume that clinicians will keep these values in mind. The lack of formal instruction on the standards for surrogate decision-making may contribute to adoption of surrogate archetypes because surrogates rely on their own perceptions about their role to guide decision-making, a consequence of which is deviation from accepted ethical standards. To navigate these potential pitfalls, clarification of the surrogate role and more explicit delineation of priorities and values are required upfront.

Although few studies have examined surrogate decision-making in the SICU, there is an extensive literature on the perspectives of surrogates in the pediatric ICU, where the use of surrogates for minors is ubiquitous. Several studies in this setting have demonstrated the preference of parents for shared decision-making.<sup>23,24</sup> In this collaborative process, surrogates and clinicians work together to make health care decisions, incorporating the best available scientific evidence with information about the patient's values, goals, and preferences. A joint policy statement from the American College of Critical Care Medicine and the American Thoracic Society in 2016 advocated shared decision-making as the default approach and noted the importance of establishing a partnership with surrogates early in the ICU stay.<sup>25</sup> Applying this model, surgeons and intensivists can play a pivotal role by advising surrogates early on that their primary responsibility is to focus on the patient's values and that the medical team will provide recommendations that are consistent with

those values. This model may standardize the approach to decision-making and promote decisions that are informed by the patient's values, irrespective of the surrogate's archetype.

**Limitations.** Participants were from a single academic medical center; thus, their experiences may differ from those of surrogates in other settings. Although participants were offered in-person interviews, all elected to have telephone interviews, which limited detection of nonverbal cues. Nonetheless, telephone interviewing is a valuable methodologic tool in phenomenologic research and is a viable alternative for data collection when face-to-face interviews are not feasible.<sup>26</sup> The convenience of telephone interviews allowed us to include surrogates who may have been otherwise unable or unwilling to participate. This study did not examine whether there were differences between surrogates for patients who had emergent versus elective operations. The interviews were performed several weeks after the participants made decisions for a patient in the SICU, which may have introduced recall bias. Seven surrogates could not be reached; their experiences may have differed from those who were interviewed, which is a potential source of selection bias. This study focused solely on surrogates' perceptions and did not explore the perceptions and experiences of surgeons and intensivists with surrogate decision-making. The style of intensivists while working with surrogates may influence how surrogates perceive their role, but that topic could not be addressed from these data. Future research studies are needed to better characterize physician-surrogate interactions in the SICU. Finally, only 2 participants had been surrogates for a patient who died in-hospital; furthermore, in both instances in which surrogates declined to be interviewed, the patient had died during the hospitalization. Therefore, it is not clear whether this model is applicable to end-of-life decision-making.

In conclusion, the Clinical Facilitator and Preference Advocate archetypes represent 2 unique approaches to the surrogate decision-maker role. Assumption of these archetypes appeared unrelated to the surrogate's awareness of the patient's values and, at times, did not meet the ethical standards for surrogate decision-making. Adoption of the Clinical Facilitator archetype and consequently devaluing the importance of patients' preferences in surrogate decision-making may diminish patient autonomy. Future work is needed to identify factors related to this phenomenon and

determine whether explicitly clarifying the surrogate role can promote decisions that better align with patients' values.

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