

# Family Surrogate Decision-making in Chronic Critical Illness: A Qualitative Analysis

Karen O. Moss, PhD, RN, CNL  
Sara L. Douglas, PhD, RN  
Eric Baum, DNP, NP-C  
Barbara Daly, PhD, RN

**BACKGROUND** Caring for an adult with chronic critical illness is a difficult undertaking. Family surrogates are tasked with decision-making on behalf of their loved one, particularly during acute-on-chronic illness episodes. Critical care nurses are well positioned and well qualified to facilitate this process.

**OBJECTIVE** To explore family surrogate decision-making for people with chronic critical illness.

**METHODS** In this qualitative study, interviews were conducted with family surrogates (n = 7) as part of a larger descriptive, longitudinal study (N = 264). Content analyses were guided by Miles and colleagues' methods of data analysis.

**RESULTS** Family surrogates serving as decision makers for a spouse or another adult loved one were mostly female. Although decision-making was often described as "frustrating," most surrogates reported that they were "comfortable" with this role. Major decision-making themes were "communication as key in decision-making," "impact of past experiences," and "difficulties and coping." Advice from family and friends, health care providers (such as nurses), and faith or spirituality were significant resources for coping with decision-making challenges.

**CONCLUSIONS** Results support recent recommendations of the National Academy of Medicine that endorsed shared decision-making. Data also support development of more effective team communication and decision support strategies, particularly addressing consistency and continuity. Critical care nurses can use their expertise to positively influence these outcomes. (*Critical Care Nurse*. 2019;39[3]:e18-e26)

**M**omentum to recognize the increasing number of family members caring for a loved one with chronic illness has grown in recent years.<sup>1,2</sup> More than 39 million people in the United States are informal caregivers for an adult, 59% of whom provide care for an individual with a long-term physical condition.<sup>3</sup> These family caregivers are sometimes required to make decisions with, or on behalf of, their loved one experiencing acute-on-chronic illnesses leading to extended hospitalization and intensive care unit (ICU) admissions. "Chronically critically ill" describes these patients, reflecting extended periods of mechanical ventilation and predisposition to high readmission, morbidity, and mortality rates after discharge from the hospital.<sup>4,5</sup> During these stressful experiences, family members often take on the role of surrogate decision maker for their loved ones. These stays in the critical care environment

present unique, extended, and repeated decision-making challenges for patients, families, and health care providers alike.<sup>6</sup>

Complexity science was used in the design of the original study of which the current project was a part. It offers a framework for understanding phenomena such as family surrogate decision-making occurring within systems such as the ICU.<sup>7</sup> It views the system as a forceful, living social system bound by a common purpose (caring for the critically ill), in which human agents (patients, family surrogates, and health care providers) constantly interact while exchanging information and adjusting behavior.<sup>7,8</sup> The original study was designed to reflect a complexity framework,<sup>7</sup> whereas this qualitative project was not designed to reveal antecedents or process elements. Adaptation of complexity science requires examination of the integrated system as a whole that is constantly changing.<sup>7</sup> Application of this theory is expected to reveal a deeper understanding of how family surrogates make decisions for the chronically critically ill within a complex health care system.

Family-centered care has been defined as an approach to health care that is respectful of and responsive to an individual family's values and needs.<sup>9</sup> Because of the level of family involvement in care of the chronically critically ill, it has been proposed that family-centered care be included as part of high-quality care in the intensive care environment, and that high-quality family-centered care be considered a basic skill for all ICU clinicians,<sup>9</sup> especially critical care nurses. Prolonged critical illness

of a loved one has an enormous psychological effect on family members, possibly including post-intensive care syndrome.<sup>9,10</sup> This syndrome includes symptoms of anxiety, acute stress disorder, posttraumatic stress, depression, and complicated grief.<sup>10</sup> Diversity in patient and family characteristics—including age, gender, ethnicity, and religion—adds to the complexity of providing adequate communication

**Family surrogates have an integral role and support in the care of the chronically critically ill.**

for surrogate

decision-making, particularly near the end of life.

Although several investigations have documented the importance of communication with ICU families, little is known about the experience of family members of long-stay ICU patients facing important decisions. The purpose of this article is to describe the experience of surrogate decision-making for chronically critically ill adults.

## Methods

### Design

Face-to-face interviews were conducted with family surrogate decision makers (n = 7) of chronically critically ill adult patients who lacked decision-making capacity. Interviews took place either while the patient was in the ICU or after he or she was discharged to another unit within the medical center. Family surrogates underwent an informed consent process before being interviewed. They represented a subset of participants in a larger longitudinal, descriptive study that examined predictions of transitions to end-of-life care by physician, patient, and family characteristics as related to outcome expectations and evaluation of treatment effectiveness. The design and methods of the original study, including participant recruitment, are fully described in a previous article.<sup>7</sup> Family surrogate decision makers were selected as a convenience sample from the larger study sample on the basis of their willingness to participate.

The interview guide shown in Table 1 contains the questions asked of participants about their experiences as surrogate decision makers. The research team developed this guide on the basis of the premise of complexity science and the researchers' experiences with the surrogates while collecting data for the larger quantitative study. To maintain consistency, interviews were uniformly conducted by a research team member (E.B.) who was trained in the conduct of interviews via formal coursework and research experience. Interviews were audio-recorded with the

---

## Authors

*Karen O. Moss is an assistant professor in the College of Nursing at The Ohio State University, Columbus, Ohio.*

*Sara Douglas is Arline H. & Curtis F. Garvin Professor of Nursing Excellence and Assistant Dean of Research, Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, Ohio.*

*Eric Baum is a certified nurse practitioner, University Hospitals Cleveland Medical Center, Cleveland, and a doctoral candidate, Frances Payne Bolton School of Nursing, Case Western Reserve University.*

*Barbara Daly is Gertrude Perkins Oliva Professor in Oncology Nursing, Frances Payne Bolton School of Nursing, Case Western Reserve University, and a clinical ethics consultant, University Hospitals Cleveland Medical Center.*

*Corresponding author: Karen O. Moss, PhD, RN, CNL, College of Nursing, The Ohio State University, 1585 Neil Avenue, Columbus, OH 43210 (email: moss.391@osu.edu).*

*To purchase electronic or print reprints, contact the American Association of Critical-Care Nurses, 101 Columbia, Aliso Viejo, CA 92656. Phone, (800) 899-1712 or (949) 362-2050 (ext 532); fax, (949) 362-2049; email, reprints@aacn.org.*

**Table 1** Interview guide

**Interview questions and prompts**

1. Can you tell me a little about this experience (of having a loved one in the intensive care unit)?
  - a. How has it been for you? Is this your first experience? Are others helping you with this?
  - b. Have there been any good/rewarding experiences?
  - c. Some negative/stressful experiences?

2. Are you being asked to make/Have you made decisions on your loved one's behalf?
  - a. How much have you been involved in specific decisions for your loved one's care?
  - b. How has this been for you/How do you feel about this?

If responses to question 2 are positive or mixed:

3. How much do you think your input/opinions affected your loved one's care here?
  - a) Tell me about some specific decisions you were involved in making ("decision points")
  - b) Were you given alternatives in these situations? What were they?
  - c) Is this something you were comfortable with? Why or why not?

5. Decision process:
  - a) How did you come to a decision in these situations?
  - b) Did you decide alone or did you discuss with other people?
  - c) Did you feel that the choices you were offered were equally good? Or was one obviously better?

6. Information:
  - a) Did you feel you had enough information to make this choice well? What else would you have wanted to know?
  - b) What information was most useful to you in making decisions for your loved one? (Information about potential outcomes? Prognosis? Your loved one's return to their previous state of health? Their quality of life?)
  - c) How much did information from the doctors influence your decision-making in this case (refer to example)?
  - d) What about what you thought your loved one's wishes might be?

If responses to question 2 are negative:

4. Is that a correct understanding on my part? What do you mean by that?
  - a) Were you offered decisions/alternatives you were reluctant to make? Did you feel you were not involved at all, or have there merely been no choices to make?
  - b) Would you have wanted to be more involved with decision-making? Why? In what way?

If surrogate wanted more input:

5. What do you think prevented this from happening?
  - a) What would you have changed about the whole process of making decisions for your loved one?
  - b) How could this process be made easier for other people in your situation?

6. Do you think your loved one's care/outcomes would have been different if you had had more say in his/her care? How?

If surrogate did not want decision-making input:

7. Why do you think that is?
8. Is there more information you could have had that would have made you more comfortable with making decisions? What would it have been? (Patient's own wishes, information about potential outcomes? Prognosis? Your loved one's return to their previous state of health? Their quality of life?)
  - a) Would talking it over with someone have helped you be more comfortable with making decisions? Whom? Why or why not?
  - b) What do you think your loved one would think about you making choices for him/her?

interviewees' permission. The average duration of the interviews was 49 minutes (range: 45-105 minutes). The number of interviews conducted was based on our goal of determining high-level, overarching themes through data saturation. Guest and colleagues<sup>11</sup> recommended that at least 6 interviews be conducted for an exploratory, descriptive study such as this one. At 7 interviews, new themes no longer emerged. This study was approved by the institutional review board of the study site.

### Analysis

Audio-recordings of the interviews were transcribed verbatim using an institutional review board-approved

vendor. Transcriptions were uploaded into Dedoose software, version 8.0.35 (SocioCultural Research Consultants, LLC), a web-based application for managing, analyzing, and presenting qualitative and mixed-methods research data. Data were analyzed using conventional content analysis,<sup>12,13</sup> guided by Miles and colleagues' methods of qualitative analysis.<sup>14</sup> Codes were derived both deductively from responses provided by the family surrogates and inductively on the basis of the researchers' experiences, and then grouped by categories and organized into larger themes.<sup>14</sup> Two investigators (K.O.M. and B.D.) independently coded the transcripts and then met to discuss coding definitions and assignments.

**Table 2** Patient and family surrogate characteristics

Patients (n=7)	Value <sup>a</sup>
Age, mean (range), y	58 (23-69)
Sex	
Male	4 (57)
Female	3 (43)
Race	
White	4 (57)
Black	3 (43)
Intensive care unit (ICU)	
Medical	3 (43)
Surgical	1 (14)
Neuroscience	3 (43)
Admission diagnosis	
Cardiac/thoracic/vascular	1 (14)
Neurologic	3 (43)
Respiratory	1 (14)
Infectious disease	2 (29)
Living will: yes	5 (71)
Do not attempt resuscitation: yes	2 (29)
Durable power of attorney: yes	6 (86)
Length of ICU stay, mean (range), d	9.6 (4-14)
Length of hospital stay, mean (range), d	24.7 (11-37)
Place of discharge <sup>b</sup>	
Rehabilitation	4 (57)
Home	1 (14)
Death (did not survive after ICU hospitalization)	1 (14)
Goal of care at discharge or death <sup>c</sup>	
Maintain cure or survival	6 (86)
Transition to end-of-life plan	1 (14)
<b>Family surrogates (n=7)</b>	
Age, mean (range), y	67.7 (43-86)
Sex	
Male	1 (14)
Female	6 (86)
Race	
White	4 (57)
Black	3 (43)
Marital status	
Married	4 (57)
Not married	3 (43)
Relationship to patient	
Spouse	4 (57)
Other	3 (43)
Religious affiliation	
Catholic	1 (14)
Protestant	5 (71)
No preference	1 (14)
Employment status	
Employed	2 (29)
Retired	5 (71)
Income <sup>b</sup>	
\$21 000-\$49 999	4 (57)
\$50 000 or greater	1 (14)

<sup>a</sup> Values are expressed as No. (%) unless otherwise indicated.

<sup>b</sup> Missing data.

<sup>c</sup> Goal as assessed by research team on the basis of treatment level documented in the medical record.

Disagreements about coding were resolved through discussion. The first round of coding was conducted using the software. The researchers made notes in the software to indicate their thoughts during analysis. A second round of coding was conducted using a hard copy of grouped codes exported from Dedoose. Codes were then highlighted and reorganized as necessary to make meaning of words and phrases shared by the family surrogates for a third round of coding.

## Results

### Patient Characteristics

More than half of the patient sample was male (57%) and white (57%). Ages ranged from 23 to 69 years (mean 58 years) at the time of hospital admission (Table 2). As noted in Table 2, most (71%) did not have medical interventions limited by a “Do Not Attempt Resuscitation” order, and for most (86%) the goal of care remained focused on survival. One patient did not survive after ICU hospitalization. Of the 6 patients alive at discharge, 1 died within the first month after discharge and 4 had died by the third month after discharge.

### Family Surrogate Characteristics

Family surrogates were mostly female (86%) caring for a spouse (57%) or another adult individual (43%), such as an adult child. Family surrogates’ ethnicity paralleled that of the patients. Most family surrogates were retired (71%), with 4 of them having an income of less than \$50 000 annually. The majority of family surrogates resided with their loved one (86%) before the current hospitalization. Most identified themselves as caregivers (71%) for their loved one with chronic critical illness before hospitalization. Family surrogates reported their health as either good (n = 4), very good (n = 2), or fair (n = 1).

### Major Decision-making Themes

Major decision-making themes derived were “communication as key in decision-making,” “impact of past experiences,” and “difficulties and coping.” Most family surrogates were “comfortable” with their role as surrogate decision maker. However, this responsibility involved challenges, some of which were alleviated by health care providers. Other resources such as family support and faith or spirituality also provided decision-making support for family surrogates.



### Communication as Key in Decision-making.

Family surrogates expressed the importance of communication that supported their decision-making. An example was when a family surrogate was asked if there was a time at which he was more involved or informed regarding decision-making for his loved one. He responded, “No, because I was [always] involved. [For] every decision, they would come and explain to me what they were [going to] do, and how it was [going to] work. . . .”

Another family surrogate referenced the uncertainty involved in medical decision-making and how the health care providers guided her through it. In general, family surrogates described the support they received from the health care teams (staff, nurses, and physicians) positively. Regarding openness in communicating, a family surrogate said, “It didn’t seem like they [health care providers] hid anything, you know, and they told me [to] the best of their ability.” Another family surrogate stated that she felt that the providers had “his [the patient’s] best interest at heart,” just as she did. In several instances, the family surrogates described hospital staff, nurses, and physicians as “wonderful” and “kind.”

Importantly, family surrogates appreciated being involved in the decision-making process and the way in which health care providers took the time to explain the situation to them. This approach provided a sense of “feeling pretty involved in the process” and not being

kept in the blind about anything,” as described by the sur-

### Consistent, open communication among patients, family surrogates, and health care providers is key to ensuring optimal care for the chronically critically ill.

rogates. Nurses were trusted to provide “helpful information” and expert advice regarding decisions at hand. Home health and critical care nurses, in particular, were credited with establishing professional bonds over time. Words such as “trust” and “caring” were used to describe the physicians. Hospital staff were also described as “supportive.” Other services such as physical therapy and social work were described as influential and were appreciated by the family surrogates.

Communication with other family members was also an important aspect of decision-making. One participant said, “I would consult with my daughter, who knows his concern and knows him very well, and then we would decide what would be the best for him.” The same participant went on to say, “So, I just try not to make a

decision on my own. I try to consult with someone else before I make a decision.” This importance of the shared duty of decision-making was highlighted by this surrogate who was tasked with the major decision-making responsibility. Another example was provided by a family surrogate who stated that she would also seek out the perspective of a friend who knew her loved one well and what he would have preferred, who “can see him from a different angle that I wouldn’t see him [from].” Another surrogate, in reference to decision-making for an adult child, said, “[I] had to involve family. She has 2 kids.” The patient’s spouse had died, and as the patient’s mother, she was involved in the decision-making process. This was another example of the emphasis placed on communication with family members and the inclusion of multiple perspectives on the patient.

Whenever possible, input from the patient was integral to communication and was considered an important element in the decision-making process. For example, one family surrogate said, “I would always consider what he would have wanted” in order to do what was best for her loved one. Another participant said that she would always ask herself, “What would he have wanted?” and “What would be the best [decision]?” and then consult with another person who knew her loved one well before making a decision. Reliance on previous conversations with their loved one regarding his or her health care wishes also provided a sense of comfort to family surrogates. One of them described the process as follows: “I asked [my sisters] what their opinion was and we pretty much did what my mother wanted.” In this instance, the perspectives of other family members as well as the patient were considered in the decision-making process.

Two surrogates offered advice for improvement in communication between family members and health care providers. Common to these conversations was a need for delivery of updates via consistent lines of communication. The family surrogate suggested that physicians communicate with the same family members consistently. Another area for improvement identified was communication between the various levels of physicians on the medical team. One family surrogate described it as the need for accurate information to be shared among the team(s) of physicians.

**Impact of Past Experiences.** Family surrogates often reflected on previous end-of-life or decision-making experiences as they discussed their current role

as decision maker. They referenced experiences with the death of loved ones, what these experiences meant to them, and the ways these experiences shaped their perspectives on their current decision-making roles. One family surrogate stated,

My mother just passed away. I made decisions [related] to what to do with her—hospice and whether to put her on life support or not, and [now] that my wife's in here, pretty much I'll have to make the decisions for her right now.

This comment reflected the surrogate's previous role as decision maker. Another family surrogate stated,

When my mother died, she and my father were both [occupation] from [college], and I thought when my mother died I was [going to] die . . . and a little angel came on my shoulder and said '[Family Surrogate], thank God you had her this long.' Since then, my 2 husbands have expired, 2 brothers have died, and I have buried 3 people in my family and I've just made a decision.

For this family surrogate, this reflection was an example of meaning making as well as reliance on faith or spirituality.

Some instances were described in which past decision-making experiences were not pleasant, but nonetheless the surrogates felt that they contributed meaningfully to the decisions at hand. Another surrogate who was caring for her father described a past experience as follows:

[Patient's father] had emphysema and [the patient] was part of the family that decided to turn off his ventilator, and he died. [The patient] told me a couple of years ago he still feels guilty about that decision. I guess that's why I wanted to make sure it was my decision and not put that on [the patient].

Family surrogates drew on professional experiences as they made decisions. This was especially true when the surrogate or another family member was a health professional. One surrogate relied on advice from her daughter, a physician, to assist with decision-making. This physician family member had the professional knowledge and experience to assess the various options

such as the one at hand regarding discharge to rehabilitation versus discharge to home.

**Difficulties and Coping.** The terms *frustrating* and *stressful* were sometimes used by family surrogates to describe the process of making decisions for their loved one. The challenges that accompany the decision-making process can be iterative, demanding constant assessment and reevaluation. One family surrogate said, "They want to do a feeding tube again, and I'm struggling with that decision and I'm [going to] wait a couple of days because he is more awake now than he was last time, and maybe he will be able to eat again." Similarly, surrogates struggled with decisions such as nursing home care versus care at home. For one surrogate, having to make such decisions was also a reminder of "the uncertainty of not knowing what tomorrow is [going to] bring."

Surrogate decision makers can be confronted with seemingly minor challenges whose removal might make a significant difference in the surrogate's quality of life. For example, one surrogate described the difficulties of air travel and having to sleep on a couch while the patient was hospitalized. For surrogates who are reluctant to leave their loved one's bedside or may lack access to resources to enable them to rest in a comfortable bed, prolonged inability to obtain a good night's sleep can impair their quality of life.

Despite support systems and other provisions to assist with decision-making, family surrogates often described decisional regret. An example was a surrogate's decision to seek medical help that resulted in an ICU stay versus treatment with medications already on hand at home. When an incident occurs that shifts the course of treatment and changes the plan of care, particularly when higher-level medical care is needed, the family may struggle with inner conflict. For families in this study, being asked to give permission for or to make decisions about invasive testing procedures such as a spinal tap or surgery often posed dilemmas.

Despite the many difficulties of caregiving, family surrogates seemed to have a largely positive experience. One family surrogate described caring for her daughter as "a lovely experience." She relied on her faith in God, referring to herself as "a child of God" as she went on to describe "little angels" that came to assist her with her needs. Another described "taking her burdens to the Lord" as a source of hope and support during difficult

**Table 3** Themes, categories, and excerpts

Theme	Category	Subcategory	Excerpt
Communication as key in decision-making	Difficulties	Decision-making	"It is frustrating and it is kind of mind-boggling to make decisions for other people . . ."
		Health care providers	"My only issue is communication between interns, residents, doctors. They may be writing stuff down, but they're not talking to each other, and a perfect example of that is when he was in [the] ICU."
	Satisfaction	Family involvement	"I like discussions with the family, to hear everybody's feelings and let everybody know [that] you can't be selfish. You know she's been sick. She's tired. We love her, but we can't just keep pushing stuff on her."
			"I converse with my children. We all make the decisions together. I have 2 sons and a daughter, and we also have discussed this with him many times, as far as what he wants to do. So we know where he stands and that's what we'll do."
			"Then I would consult with someone who knew him well and then I would arrive at the decision that I would make."
	Health care provider role	"They [health care providers] ask me everything, and my opinion first."	
"I felt that everything was always explained very carefully and thoroughly, and [I] really didn't have too many questions about any of the procedures."			
Including the patient perspective	"You know we talked before this [happened] and I know what she wants." "I take into consideration what [the patient] would have wanted, and then I consult with someone else before I make a decision, and have them explain it to me from their point of view."		
Impact of past experiences	Meaning making	Reflection on lessons learned	"This is my first time making a decision for him. Now when my husband was sick, I had to make decisions for him, but I took under consideration the same [aspects] that I'm doing here, 'What would he have wanted?' and then 'What would be the best [decision]?'"
		Influencers	"Once they said 'dialysis. . .' I'm an [allied health professional] and I know people on dialysis go to dialysis every day, so I think I didn't have [any] trouble with that." "When we did our living will, I made a promise that I would not let him stay alive on machines, and after he had his last surgery for an abscess, this is what you see, and you know I didn't want to see him like this, so I requested to stop the treatment."
Difficulties and coping	Comfort	Faith/spirituality	"It's always in God's hands." "Whatever happens, I'll just thank God I had [the patient] this long. So since [then], I have that in my mind, and feel and think like that—nothing's [going to] be as hard as it was for my mother to die."
	Challenges	Health care providers	"It's an ongoing complication that they're just having a lot of trouble resolving, because these doctors have not seen anyone like him before. They have not seen someone who has such [blood] pressures. They can't find a happy medium. They can't find the correct thing, so it's frustrating."

Downloaded from <http://aacnjournals.org/ccnonline/article-pdf/39/3/18/119225/e18.pdf> by guest on 06 December 2024

times. Table 3 provides examples of the themes and categories derived from this analysis.

## Discussion

Decision-making is rarely simple. Although the sample size of this study was small, data provided by these

interviews support recommendations regarding improvements in communication for critically ill patients and their families.<sup>9</sup> It was important to the family surrogates in this study that they were involved in the decision-making process. This study adds to the literature on understanding surrogate decision-making for the

chronically critically ill in particular and highlights the importance family surrogates place on the perspectives of other family members, friends, and health care providers. This theme suggests a need to assure family surrogates that they can include other support people such as other family members in the family meetings. Critical care nurses should advocate for including additional family members or loved ones in these meetings and also encourage them to get sufficient rest in order to be better physically and psychologically prepared to advocate on behalf of their loved one, promoting good caregiver quality of life.

Results of this study support the design of more effective communication processes and decision support strategies for health care teams, with a goal of reduced stress and conflict while facilitating optimal care, including care near the end of life.<sup>6,15</sup> Nurses' almost continuous presence at the bedside provides opportunities for them to engage with families in ways that are less feasible for other members of the health care team.<sup>16</sup> Critical care nurses are particularly influential in helping ameliorate psychological symptoms.<sup>17</sup> Input from these nurses during the acute phase of illness is essential, as they possess the knowledge and skills needed to serve as patient and family advocates while helping them to navigate the intricacies of health care decision-making. Their unique role at such a crucial time in the illness trajectory makes them well suited to spearhead interventions to improve communication between family surrogates and members of the health care team.<sup>15</sup>

Specifically, critical care nurses are well positioned to facilitate high-quality surrogate decision-making by educating the family on the role of the surrogate, organizing regular family and multidisciplinary team meetings, preparing the family before each meeting, providing emotional support and prompts during the meetings, and being present for "the meeting after the meeting."<sup>16</sup> Whether or not the surrogates in this study had a health care background, they attempted to understand the technical terminology used in conversations with health care providers; it was important to them to be able to "speak the language" of health care. Critical care nurses can provide interpretation and explanation of overly technical language, serving as a bridge to improved communication with members of the health care team.

Although discussions of shared decision-making tend to focus on the patient and the clinician, when surrogate

decision-making is required, family preferences become an important part of the conversation. The ability to reach out to family and friends for decision-making support seemed to provide a sense of comfort and peace to family surrogates. These results support recent recommendations of the National Academy of Medicine that endorsed shared decision-making as a key aspect of patient-centered care.<sup>18</sup> Research demonstrates that prognoses and likely clinical outcomes are poorly understood by family surrogates of chronically critically ill patients. This situation may stem from inadequate communication among patients, clinicians, and families.<sup>1</sup> Family surrogates expect to receive current and intelligible information free of inconsistencies from an organized health care team.<sup>19</sup> The critical care nurse can facilitate this conversation, particularly when discussions involve goals of care. Treatment decision-making can have a negative emotional effect on family surrogates that is often substantial and typically lasts from months to years.<sup>20</sup> Critical care nurses can provide emotional support and coping strategies through referrals, additional discussions, and reassurance, which can reduce or eliminate the potential for anxiety, depression, and even posttraumatic stress disorder among family surrogates.<sup>17</sup>

## Limitations

This study has inherent limitations. Participants were selected as a convenience sample from the larger study on the basis of their willingness to participate in the interviews. Therefore, the results are likely biased.<sup>21</sup> In particular, these interviews do not represent surrogate decision makers whose loved one died in the ICU after a decision to limit life-sustaining interventions. A strength of this study, however, is its ability to capture the experiences of the family surrogates of chronically critically ill adults in their own words as they carried out their roles as surrogate decision makers, thus providing real-time data. Family surrogates were able to openly share their experiences in a nonthreatening environment. However, the fact that these interviews were conducted in the health care setting may have limited the caregivers' perceived freedom to divulge their sincerest thoughts. Future research in this area could be conducted in the caregivers' natural environment (such as their homes), which might lead to more open responses regarding their role as surrogates, with less of a focus on health care providers.



## Future Implications

Although “in the moment” it appeared that family caregivers had a largely positive experience with decision-making, the long-term impact of this process is unknown. According to McAdam et al,<sup>17</sup> even though family members’ symptoms of posttraumatic stress disorder (depression and anxiety) were significantly decreased 3 months after the intensive care experience (compared with during the experience) regardless of the patients’ final disposition, many still had significant risk for anxiety, depression, and posttraumatic stress disorder at 3 months, placing these family members at risk for long-term negative psychological health outcomes. The use of mixed-methods analyses to study this population of surrogate decision makers to determine the impacts of family caregiving both “in the moment” and longitudinally may provide more in-depth understanding of their perspectives. It would also be important to determine whether these results differ between family caregivers who are involved versus not involved in the decision-making process and between those who are versus are not distance caregivers.

## Conclusions

This study provides further evidence to support the need for enhanced communication strategies related to decision-making for the chronically critically ill. It adds to the growing body of literature in this area with qualitative perspectives from the family surrogates. Armed with this information, nurses and their health care teams can improve their understanding of family surrogates’ perspectives and inform intervention studies that are translated into clinical practice. Such interventions may enhance the family surrogates’ ability to participate fully in care and treatment decisions concerning their loved one.<sup>22</sup> This knowledge will help health care providers to more efficiently meet the needs of the chronically critically ill. Improved outcomes of family surrogate decision-making can help reduce the burden experienced by family surrogates, enabling them to better care for themselves as well as their loved ones. **CCN**

### Financial Disclosures

This study was funded through the National Institutes of Nursing Research (R01NR013322). Karen O. Moss was funded by a T32 fellowship from the National Institutes of Health in Symptom Management and Palliative Care Research in Adults with Advanced Disease (4T32NR01421304) in the Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, Ohio.

## eLetters

Now that you’ve read the article, create or contribute to an online discussion about this topic using eLetters. Just visit [www.ccnonline.org](http://www.ccnonline.org) and select the article you want to comment on. In the full-text or PDF view of the article, click “Responses” in the middle column and then “Submit a response.”

## See also

To learn more about families in critical care, read “Family Members’ Experiences With Bereavement in the Intensive Care Unit” by Jones et al in the *American Journal of Critical Care*, July 2018;27:312-321. Available at [www.ajconline.org](http://www.ajconline.org).

### References

1. Nelson JE, Mercado AF, Camhi SL, et al. Communication about chronic critical illness. *Arch Intern Med*. 2007;167(22):2509-2515.
2. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press; 2015.
3. National Alliance for Caregiving, AARP Public Policy Institute. Caregiver profile: the typical caregiver. 2015. [http://www.caregiving.org/wp-content/uploads/2015/05/2015\\_CaregivingintheUS\\_Final-Report-June-4\\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf). Accessed March 7, 2019.
4. Daly BJ, Douglas SL, Kelley CG, O’Toole E, Montenegro H. Trial of a disease management program to reduce hospital readmissions of the chronically critically ill. *Chest*. 2005;128(2):507-517.
5. Girard K, Raffin TA. The chronically critically ill: to save or let die? *Respir Care*. 1985;30(5):339-347.
6. Moss KO, Douglas SL, Baum E, Daly B. A qualitative analysis of family surrogate decision making in chronic critical illness. *J Pain Symptom Manage*. 2017;53(2):425.
7. Daly BJ, Douglas SL, O’Toole E, et al. Complexity analysis of decision-making in the critically ill. *J Intensive Care Med*. 2018;33(10):557-566.
8. Miller WL, McDaniel RR Jr, Crabtree BF, Stange KC. Practice jazz: understanding variation in family practices using complexity science. *J Fam Pract*. 2001;50(10):872-878.
9. Gerritsen RT, Hartog CS, Curtis JR. New developments in the provision of family-centered care in the intensive care unit. *Intensive Care Med*. 2017;43(4):550-553.
10. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome—family. *Crit Care Med*. 2012;40(2):618-624.
11. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006;18(1):59-82.
12. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334-340.
13. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
14. Miles MB, Huberman AM, Saldana J. *Qualitative Data Analysis: A Methods Sourcebook*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2014.
15. Iverson E, Celious A, Kennedy CR, et al. Factors affecting stress experienced by surrogate decision makers for critically ill patients: implications for nursing practice. *Intensive Crit Care Nurs*. 2014;30(2):77-85.
16. White DB. Rethinking interventions to improve surrogate decision making in intensive care units. *Am J Crit Care*. 2011;20(3):252-257.
17. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk intensive care unit patients. *Am J Crit Care*. 2012;21(6):386-394.
18. Alston C, Berger ZD, Brownlee S, et al. Shared decision-making strategies for best care: patient decision aids. 2014. <https://nam.edu/perspectives-2014-shared-decision-making-strategies-for-best-care-patient-decision-aids>. Accessed March 7, 2019.
19. Azoulay E, Pochard F, Chevret S, et al. Meeting the needs of intensive care unit patient families: a multicenter study. *Am J Respir Crit Care Med*. 2001;163(1):135-139.
20. Wendler D, Rid A. Systematic review: The effect on surrogates of making treatment decisions for others. *Ann Intern Med*. 2011;154(5):336-346.
21. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th ed. New York, NY: Lippincott, Williams & Wilkins; 2017.
22. McAdam JL. Symptom experiences of family members of intensive care unit patients at high risk for dying. *Crit Care Med*. 2010;38(4):1078-1085.