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How Surrogate Decision-Makers for Patients with Chronic Critical Illness Perceive and Carry Out Their Role

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Abstract

Objectives: Family members commonly make medical decision for patients with chronic critical illness. This study examines how family members approach this decision-making role in real time.

Design: Qualitative analysis of interviews with family members in the intervention arm of a randomized controlled communication trial.

Setting: Medical Intensive Care Units at four US hospitals.

Participants: Family members of patients with chronic critical illness (adults mechanically ventilated for ≥ 7 days and expected to remain ventilated and survive for ≥ 72 hours) who participated in the active arm of a communication intervention study.

Interventions: Family members participated in at least two content-guided, informational and emotional support meetings led by a palliative care physician and nurse practitioner.

Measurements and Main Results: Grounded theory was used for qualitative analysis of 66 audio-recordings of meetings with 51 family members. Family members perceived their role in 4 main ways: voice of the patient, advocate for the patient, advocate for others, and advocate for oneself. Their decision making was characterized by: balancing goals, sharing their role, keeping

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perspective, remembering previous experiences, finding sources of strength, and coping with various burdens.

Conclusions: Family members take a multifaceted approach as they participate in decision-making. Understanding how surrogates perceive and act in their roles may facilitate shared decision-making among clinicians and families during critical care.

Keywords

Chronic critical illness; surrogate decision-makers; intensive care units; caregivers; interviews; qualitative analysis

Introduction

Patients with chronic critical illness require prolonged mechanical ventilation and intensive care due to respiratory failure and multi-organ dysfunction (1, 2). They face an uncertain disease trajectory and complicated medical decisions with life and death consequences. As with most critically ill patients, they are often unable to make treatment decisions and decision-making falls to their family members or other surrogates (3–5). Some studies of surrogate decision-making have focused on the degree to which surrogates accurately represent the wishes of critically ill patients with an underlying assumption that surrogates' treatment decisions ought to reflect patient preferences (6). Other studies have measured the impact of the decision-making process on family members with attention focused on psychological distress, regret, and decisional burden (7–10). Current research rarely includes the actual voice of the surrogates as they grapple with decisions. This study examined audio-recorded goals of care discussions with family members of patients with chronic critical illness and described how families experience decision-making, including the challenges they face, the complexities they perceive, and how they cope (11).

Materials and Methods

This study was conducted as part of a randomized controlled trial of a communication intervention for families of patients with chronic critical illness (11). The main study and qualitative analyses underwent review and received IRB approval at each study site (NCT01230099).

Recruitment occurred from December 2010 to October 2014 in Medical Intensive Care Units at four US hospitals (11, 12). Written consent was obtained from surrogates for their own research participation and for incapacitated patients. Participants from the intervention and control groups received a validated brochure on chronic critical illness (<http://www.myicucare.org/Adult-Support/Pages/Chronic-Critical-Illness.aspx>) (13). The intervention group participated in at least two content-guided meetings with palliative care specialists who were part of the Supportive Information Team (SIT) (11). In these meetings, clinicians assessed surrogates' prognostic awareness, shared prognostic information, and gauged surrogates' readiness to make treatment decisions.

A consecutive subsample of surrogates consented to audio-recording of the meetings from July 2011 through August 2013 and were eligible for this analysis (12).

Audio-recorded meetings were transcribed verbatim and analyzed with Atlas.ti software. We used a grounded theory approach, an inductive method of data analysis, in which the themes were built from coding of the data and used to develop a theoretical framework (14, 15). An interdisciplinary team of 6 investigators conducted an initial analysis of two random samples of audio recorded SIT meetings to identify concepts and categories and establish the preliminary coding framework (12). Initial codes were subsequently integrated into one single framework. Upon further review of the data, 2 coders completed the coding process.

Results

Participant characteristics

Of 76 surrogates for 59 patients who provided consent for audio-recording of the SIT meetings for the qualitative study, 66 meetings involving 51 surrogates (67%) for 43 patients (73%) were included in the final analysis. Table 1 describes patient and surrogate characteristics.

Themes

Six themes emerged from coding the conversations in these meetings (12). These coding themes related to the following concepts: 1) Receptivity of the family to information about the patient's condition, 2) Tendency to deflect or reject information through denial or disbelief, 3) Emotional reactions of family members, 4) Tendency to reflect on the patient's longstanding character when deciding what to do on the patient's behalf, 5) Reflections on their role as surrogate decision-maker, and 6) Considerations about balancing needs and concerns of others. An analysis of themes 1–4 was published previously (12). For the analysis reported here, we focus on themes 5 and 6 (labeled Themes I and II in this analysis) because these themes address surrogates' perspectives regarding their complex role and strategies as surrogate decision makers. The themes and subthemes are outlined in Table 2 and illustrative quotes from recorded SIT meetings that reflect these themes are presented below and in Supplemental Table 1.

Theme I: Reflection on their role as surrogate decision-maker

In quotes pertaining to their role, we identified four main subthemes: (1) Voice for the patient; (2) Advocate for the patient; (3) Advocate for others; and (4) Advocate for oneself.

Subtheme A: Voice for the patient—To convey patients' wishes and goals of care to the medical team, surrogate decision-makers often quoted the patient's prior words.

She wants to go home. That's the first thing said, "I want to go home."

Quotations of negative preferences were often emphasized.

You know, I mean, he specifically said, "if I have to live with a tube in my mouth and I can't... and I'm going to be paralyzed, I don't want to live. Don't do that to

me... he specifically said to me he didn't want to be hooked up to machines or in a chair.

Subtheme B: Advocate for the patient—Surrogates often used the term “advocate” during SIT team discussions. This advocacy role extended beyond conveying patients’ wishes to the healthcare team. Either by taking the initiative to request critical care or signing consent for procedures, respondents often perceived themselves as a champion or defender of the patient’s well-being.

One mother said,

Whatever they need to do, let ‘em go ahead and do it because whatever it is, it’s gotta be something that’ll help her. You ain’t gonna just come and say, “well, she needs to get this, you know, in her throat and...” you know, when it could be hindered or whatever. But, if she need it, I gotta get it done. Aint not need to waitin.

Subtheme C: Advocate for caregivers and family members—For many patients, multiple caregivers became involved in the decision-making process. The responsibility often fell to the primary surrogate to advocate for the needs and considerations of other family members, as one participant mentioned:

So, you know... we do shifts and if somebody’s got something to do, we try to have somebody else here. We also support his mom so she’s not alone...

Subtheme D: Advocate for oneself—A few surrogate decision-makers spoke of the need for self-care. The self-advocacy role became apparent when surrogates confronted limitations in fulfilling their other roles. Sometimes, the sense of responsibility toward the patient overshadowed surrogates’ considerations of their own needs. For example, one surrogate asked herself,

Should I move forward with what I have to, in **my** life? Or, do I wait a little longer ‘til I know what’s going on with...

Other times, the primary surrogate and additional family members worked closely as a team to advocate for each other’s health and well-being.

Friend: *“I think people started to realize what was happening and needed ... that I needed to pay attention, not just to him, but to me, so ... You know, so people really started making sure that I kind o’ got back on track, so that was good.”*

Theme II: Consideration about Balancing Needs and Concerns for Others

Subthemes reflected strategies that surrogates used while addressing broader needs and concerns for others. Many of the quotes may be applied to more than one category.

Subtheme A: Finding the Balance—Participants spoke of balancing several competing concerns: the patient’s conflicted preferences, one’s own perspective versus the patient’s, risks and benefits of proposed care plans, survival versus quality of life, and present needs versus future concerns (Table 2).

In the following example, a surrogate struggled between doing what he selfishly wished for the patient versus what the patient may have wanted.

Son: *"I think that you can't be that selfish a person, if they're suffering... it's best to let 'em... let 'em go."*

Surrogates spoke about the difficulty of agreeing to transitions in care when uncertainty existed regarding the patient's functional status and the risk and benefits of a proposed care plan. A concern that was particularly pressing for surrogate decision-makers of chronically critically ill patients was that they faced the responsibility of making decisions for patients who might eventually survive their illness but not be liberated from life-support (see Supplemental Material: Sample Conversation About Liberation from the Ventilator).

Subtheme B: Sharing the role—Family dynamics played a recurring role in surrogates' approaches to decision-making. Whereas some surrogates saw multiple interested family members as burdensome, many spoke about actively choosing to engage others in the conversation:

Sunday night that they told me that he had, at best a 50–50 chance to make it to Monday morning... I took the older of two brothers-in-law out... we went in the hallway, you know. 'Look,' I said, 'if things do not turn around, there may come a time in the next week or so, that they might have to make a hard decision.' I said, 'and that is definitely not one decision I'm going to make by myself.'

Subtheme C: Exhibiting a sense of perspective—Another strategy involved appreciating the importance of the big picture over details in making decisions about procedures:

He's not gonna be able to hike. He's gonna be able.. if, in this perfect world, he's gonna be on oxygen, but able to go and hang out with his friends, he can't hike with his friends, do you think that's... you don't think that's good enough? The answer is, 'it is.' It has to be. He's not gonna be able to hike anymore. He's not gonna be able to hike when he's dead either.

Subtheme D: Drawing from previous experiences—Many surrogates looked to prior experiences with surrogate decision-making for guidance in putting their current situation in perspective.

I was the medical pros... uhm, the medical proxy for my mother, as well as my aunt... and my mother died of gastric cancer... and my aunt died of heart disease. So, it was really dramatic for me to see her go through Point A to Point Z in such... in such a short period of time... my whole thing is just to go through this process and try to be as informed as possible.

Subtheme E: Finding strength—When asked the question "what keeps you going strong," some found strength in their religious faith and spirituality, others found strength within themselves.

It's hard... I think it's almost like I have to dissociate myself, just a little bit, sometimes. I'm able to, you know, do it because uhm ... Yeah. It's ... it's hard. It's hard. You know, I'm a mom of two young children., I work in a very, very, very busy practice....But I'm not unique... I think that's what keeps me grounded is that I know I'm not unique and that, you know, unfortunately, for a lot of women, that's the role that we have to play.

Subtheme F: Acknowledging burdens and challenges—Surrogates reflected on several types of “burden” and challenges when making decisions for chronically critically ill patients. Some recounted the emotional burden (often described as feelings of guilt and blame) associated with bringing the patient to the hospital or giving consent for invasive procedures, as demonstrated in this example:

I don't want to do that anymore. I... matter o'fact, that last thing about the...[the trach]. I... I wouldn't do it. Because I've signed so much for my mother. Ev-v-very surgery my mother had here...my sister, I told her, I said, 'I can't do nothing else, no more.' Because mentally, I'm exhausted. So... and a lot o' ... a little bit, I blame myself cuz I signed that... actually, took my mother to that surgery. [a little bit angry tone]

In addition to the emotional toll, a few surrogates addressed the physical exhaustion from sitting with the patient in the hospital on a daily and hourly basis. Others spoke of the financial burden and the time demands they faced in providing medical care for the patients.

Discussion

Our analysis of audio- recorded discussions examines the perspective of family members regarding their role in decision-making for chronically critically ill patients during ICU admissions at four US hospitals.

Two study results are particularly interesting. First, family members tend to look beyond the patient's health, well-being and preferences as they make decisions. They spoke of being an advocate for other family members and themselves, as well as needing to arbitrate among multiple family member's concerns. They also expressed an inclination to make decisions in concert with others.

Much of the empirical literature on surrogate decision-making compares patient and surrogate responses to hypothetical scenarios. In such studies, the accuracy of substituted judgment regarding treatment preferences is around 68% (6). One study concluded that surrogates' prediction errors often represent their own wishes for the patient (16). Surrogates find it very difficult to ignore their personal preferences due to their love and concern for the patients (4).

Our findings indicate that surrogates put extensive thought into balancing competing perspectives and preferences of patients and others who have a concern for and stake in patients' well-being. While surrogates were articulate about what the patient would or would not want, they demonstrated the tensions they face in dealing with their own as well as other

family members' needs and preferences when participating in treatment decisions. The degree to which surrogates took factors other than what the patient wanted into account provided insight into why congruence of patient and family preferences for life-sustaining treatments as measured in hypothetical studies are unlikely to be a good predictor of the extent to which surrogates' decisions will reflect patient preferences. Our analysis suggests that surrogates weigh many factors during the decision-making process that extend beyond the basic principles of substituted judgment predicated solely on respect for patient autonomy.

The second noteworthy finding is the types of burdens surrogates experience. Previous studies indicate that decision-making on behalf of critically ill patients may have long-term and serious psychological effects on surrogates (8). The ramifications of the medical decision-making process can significantly alter the family structure and affect the relationship between the family and the healthcare team (17). It is thus noteworthy that the burdens that respondents mentioned in our study were not exclusively emotional but also physical, financial and time-related. While the economic burden of chronic illness is well described in the literature (18–20), there is less attention to how these concerns should be addressed in the course of decision making.

Several prior studies have examined the use of family meetings to improve communication between clinicians and families in the ICU setting. Increased opportunities for family members to speak are associated with greater family satisfaction with physician communication and lower family-perceived conflict (21). Structured family conferences may also improve patient- and family-centered outcomes such as emotional well-being and length of stay in the ICU (22). A recent randomized trial suggested that an intervention that addressed family's emotions, concerns, needs, and communication preferences may be associated with a reduction in both hospital length of stay and family member depressive symptoms (23). The combination of content-guided family meetings and better understanding of the influences and pressures on surrogate decision-makers may help clinicians to foster a positive relationship and collaboratively formulate the best care plan for ICU patients. In a recent publication on shared decision-making in the ICU, the American College of Critical Care Medicine and American Thoracic Society Ethics Committee recommended that clinicians use a collaborative decision-making model that best adapts to patients' and surrogates' preferences (24). In working through the decision-making process with caregivers, physicians therefore need a nuanced understanding to help guide families through the social, emotional, and ethical factors that surrogates take into consideration when caring for their loved ones.

Results from our study complement the existing literature by giving insight into the complex roles that families find themselves in while making decisions on behalf of chronically critically ill patients. Our findings suggest that clinicians do well to remember that families likely feel they are filling many roles and commitments that at times may be in tension when they are in the midst of making decisions for a chronically critically ill patient.

A limitation of this study was that only 79.5% of eligible surrogates agreed to audio recording during the qualitative study enrollment period and were subsequently included in

the qualitative analysis. Surrogates who declined audio-recording of the SIT meetings could have offered different perspectives from those who provided informed consent. Yet strengths of this analysis are its representation of the views of a diverse cohort of family members and caregivers at several institutions and its occurrence while participants were experiencing actual decisions for chronically critically ill patients.

Conclusion

Clinicians cannot predict how surrogates might approach their role as decision-makers for critically ill patients who cannot consent on their own. Clinicians must be sensitive to the fact that life-sustaining treatment decisions will have profound effects both on the patient and the family. Appreciation of the interests and concerns of families such as those found in this study may allow clinicians to be more understanding, supportive and helpful during the shared decision-making process.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Characteristics of Patient and Surrogates

Characteristics	Patients	Surrogates
N	43	51
Gender, M (%)	21 (49)	14 (27)
Age, yrs, mean $\pm$ SD	57 $\pm$ 18	54 $\pm$ 13
Race		
Black	12 (28)	13 (25)
Caucasian	29 (67)	35 (69)
Asian	1 (2)	0 (0)
American Indian/ Alaskan Native	0 (0)	2 (4)
Other	0 (0)	0 (0)
Unavailable	1 (2)	1 (2)
Ethnicity		
Hispanic or Latino	3 (7)	6 (12)
Not Hispanic or Latino	40 (93)	45 (88)
Unavailable	0 (0)	0 (0)
Religion		
Catholic	8 (19)	11 (22)
Protestant	24 (56)	28 (55)
Jewish	3 (7)	3 (6)
Muslim	1 (2)	2 (4)
Other/None	7 (12)	7 (14)
Unavailable	0 (0)	0 (0)
Site		
Duke University	5 (12)	6 (12)
UNC Chapel Hill	14 (33)	17 (33)
Mt. Sinai Medical	16 (37)	18 (35)
Durham Regional	8 (19)	10 (20)
Number of chronic co-morbidities	2.77 $\pm$ 2.0	
APACHE II Score at Enrollment, mean $\pm$ SD	26 $\pm$ 5	
Predicted 1-Year Mortality, %, mean $\pm$ SD*	57 $\pm$ 22	
Died in Hospital	16 (37)	
Decision-maker Status		
Primary Surrogate		41 (80)
Additional Decision-maker		10 (20)
Relation to Patient		
Child >18 yr old		15 (30)
Parent		10 (20)

Characteristics	Patients	Surrogates
Sibling		5 (10)
Spouse/Partner		18 (35)
Other		3 (6)
Education		
No High School		1 (2)
Some High School		4 (8)
High School Graduate		9 (18)
Some College		10 (20)
College Graduate		14 (27)
Advanced Degree		13 (25)
Employment Status		
Employed		26 (51)
Unemployed (Not Disabled)		4 (8)
Homemaker		2 (4)
Retired		15 (29)
Disabled		3 (6)
Student		1 (2)

Table 2.

Main Themes and Subthemes: How Surrogate Decision-Makers Define and Approach Their Role*

Themes and Subthemes	Description
Theme I:	Reflections on their role as surrogate decision-maker
Subtheme A:	Voice for the patient i. Conveying the patient's wishes and goals ii. Emphasizing what the patient would not want
Subtheme B:	Advocate for the patient i. Involving the patient in the decision-making when possible
Subtheme C:	Advocate for caregivers and family members
Subtheme D:	Advocate for oneself
Theme II:	Considerations about balancing concerns and needs of others
Subtheme A:	Finding the Balance i. Balancing among the patient's preferences ii. Balancing one's own perspective versus the patient's iii. Balancing the risks and benefits of the proposed care plan iv. Balancing survival and quality of life versus suffering Balancing present versus future/Looking ahead
Subtheme B:	Sharing the Role i. Sharing the role ii. Importance of the family network
Subtheme C:	Exhibiting a sense of perspective
Subtheme D:	Drawing from previous experiences
Subtheme E:	Finding strength
Subtheme F:	Acknowledging burden i. Psychological burdens a. Facing External Pressure b. Facing conflicting opinions c. Feeling left out ii. Physical burdens iii. Economic burdens iv. Burden of time commitment

- Sample quotations illustrating each of these themes and subthemes are shown in Supplemental Table 1.