

The Voice of Surrogate Decision-Makers

Family Responses to Prognostic Information in Chronic Critical Illness

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Abstract

Rationale: Information from clinicians about the expected course of the patient's illness is relevant and important for decision-making by surrogates for chronically critically ill patients on mechanical ventilation.

Objectives: To observe how surrogates of chronically critically ill patients respond to information about prognosis from palliative care clinicians.

Methods: This was a qualitative analysis of a consecutive sample of audio-recorded meetings from a larger, multisite, randomized trial of structured informational and supportive meetings led by a palliative care physician and nurse practitioner for surrogates of patients in medical intensive care units with chronic critical illness (i.e., adults mechanically ventilated for ≥ 7 days and expected to remain ventilated and survive for ≥ 72 h).

Measurements and Main Results: A total of 66 audio-recorded meetings involving 51 intervention group surrogates for 43 patients were analyzed using grounded theory. Six main categories of surrogate responses to prognostic information were identified: (1) receptivity, (2) deflection/rejection, (3) emotion, (4) characterization of patient, (5) consideration of surrogate role, and (6) mobilization of support. Surrogates responded in multiple and even antithetical ways, within and across meetings.

Conclusions: Prognostic disclosure by skilled clinician communicators evokes a repertoire of responses from surrogates for the chronically critically ill. Recognition of these response patterns may help all clinicians better communicate their support to patients and families facing chronic critical illness and inform interventions to support surrogate decision-makers in intensive care units.

Clinical trial registered with www.clinicaltrials.gov (NCT 01230099).

Keywords: health communication; critical illness; mechanical ventilation; palliative care

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At a Glance Commentary

Scientific Knowledge on the

Subject: Although family surrogates and clinicians agree that prognostic information about patients' chronic critical illness is important for decision-making about continuation of intensive care, surrogates' responses to such information as communicated by clinicians in real time were not directly observed in prior research.

What This Study Adds to the

Field: This qualitative study of content-guided, audio-recorded family meetings led by skilled clinician communicators (palliative care physician and nurse practitioner) in medical intensive care units at four hospitals in two states identifies a typology of dominant and distinct responses to prognostic information: receptivity, deflection/rejection, emotion, characterization of patient, consideration of surrogate role, and mobilization of support. The study also shows that individual surrogates often respond in multiple and even inconsistent ways. Recognition of response patterns in real-time clinical context, and of the importance of the emotional subtext in clinician-family meetings, can guide development, implementation, and evaluation of strategies for all clinicians to support surrogates as they face challenges and decisions on behalf of a chronically critically ill loved one.

Chronic critical illness is characterized by prolonged and often permanent dependence on mechanical ventilation along with weakness, malnutrition, anasarca, brain dysfunction, neuroendocrine changes, repeated infections, and severe symptom distress (1). One year mortality is 50–60% (2–4), and survivors typically require custodial care after extended hospitalization (5, 6). Chronic critical illness also has profound impact on the lives and well-being of families, who are burdened by emotional and economic concerns and the strains of caregiving (7–9).

Family members are challenged by their frequent role as surrogate decision-makers for a chronically critically ill loved

one. They often lack information about prognosis (8–10). Most are unaware of the possibilities for functional and cognitive recovery, future care needs, financial burdens, or alternatives to continuing life support (10). At the same time, surrogate decision-makers report that it is difficult to hear unfavorable prognostic information (11). Seeking both candor and optimism, they experience an internal tension between informational and emotional needs (11).

In this study, we used qualitative analysis to understand and categorize the range of family responses to discussions led by palliative care specialists tasked to focus within a content-guided framework on explaining the nature and prognosis of chronic critical illness. By illuminating these responses, we hoped to inform and improve approaches to clear, sensitive, and supportive communication with surrogate decision-makers for the chronically critically ill.

Methods

This study was conducted in conjunction with a larger multisite randomized clinical trial of an intervention to improve clinician-family communication and decision-making for patients with chronic critical illness (12). The institutional review board at each study site approved the larger trial and this concurrent qualitative research.

Study Participants

Recruitment for the intervention trial was conducted from December 2010 through October 2014 in medical intensive care units (ICUs) at four hospitals in New York and North Carolina as described elsewhere (12). Adult patients were eligible if they were mechanically ventilated for 7 or more days and expected by the ICU attending physician neither to be liberated from the ventilator nor die in the next 72 hours (1). We recruited the patient's primary surrogate decision-maker and any additional decision-makers for the patient. All surrogates provided written consent for their own research participation and for patients lacking capacity, and were randomized to intervention and control groups as described later. Participants in the present qualitative study are a consecutive subsample of intervention group surrogates consenting to audio-

recording of meetings (which was optional) from July 2011 through August 2013. Clinicians also provided consent.

Supportive Information Team Intervention

Surrogates in intervention and control groups received a validated brochure addressing key aspects of chronic critical illness (13, 14). Intervention group surrogates were also scheduled to participate in at least two content-guided meetings where information and emotional support were provided within a goal-directed decision-making framework. These meetings were led by a Supportive Information Team (SIT) composed of a palliative care physician and nurse practitioner, with optional attendance by the ICU attending physician. SIT clinicians were not asked to provide a full palliative care consultation.

The first meeting (SIT-1) occurred within 4 days of enrollment, typically after 10–14 days of mechanical ventilation, an accepted definition of chronic critical illness (1). The second meeting (SIT-2) was held 10 days after SIT-1, a time by which most patients who are successfully weaned from prolonged mechanical ventilation have achieved ventilator liberation (3). SIT clinicians met formally with the ICU attending physician before each SIT meeting and, using a template-guided process, reviewed the patient's condition, prognosis, and treatment as well as the ICU team's assessment and recommendations. They met again after the meeting to provide feedback. Additional SIT meetings were conducted upon request from family, ICU, or SIT clinicians. SIT meeting protocols reflected best communication practices based on existing evidence, including asking permission before sharing prognostic information (15–17). However, SIT clinicians had flexibility to use their clinical judgment to adapt to the needs of individual surrogates. Adherence to the content in the protocol was documented at the end of the meeting by a research assistant in attendance.

Qualitative Analysis

Audio-recorded meetings were transcribed verbatim and analyzed using a grounded theory approach (18). To develop a preliminary analytic coding framework, an interdisciplinary group of six investigators (medical, nursing, and mental health

professionals) contributed expertise in critical care, ethics, palliative care, geriatrics, and psychology. These investigators independently used open and axial coding to identify concepts and categories in two successive random 20% samples of transcripts of full SIT meetings involving unique patients. The first sample of meeting transcripts was coded line-by-line. For the second sample, codes were assigned to all passages of discussion (i.e., entire exchange between SIT clinicians and surrogates, continuous or separated by only a brief interruption, on a discrete topic). Because discussion of prognostic information occurred at different points within and across meetings, coding included passages throughout transcripts. Working together, three investigators (K.L.K., J.E.N., S.P.W.) used selective coding and uniform terminology to integrate initial codes into a single framework. Coding of passages continued by two or more coders, who met to review and reach consensus on codes in each transcript. ATLAS.ti (Berlin, Germany) software allowed us to sort passages according to codes, examine relationships among codes and passages, and select quotes to illustrate concepts. We performed “member checking” by presenting the coding framework to family participants and palliative care clinicians (19, 20). We then determined frequencies by family (i.e., the patient’s primary surrogate and/or any additional decision-makers) and by meeting (SIT-1, SIT-2) for specific types of surrogate responses within this framework.

Results

Of the 74 patients who were eligible during the qualitative study period, consent for audio-recording was provided by 76 intervention group surrogates for 59 patients (80%). A total of 66 SIT meetings involving 51 surrogates (67%) for 43 patients (73%) were recorded, transcribed, and analyzed. Ten surrogates did not participate in meetings because of patient death or surrogate unavailability, and technical difficulties impaired recording or transcription for meetings involving 15 surrogates. A total of 33 palliative care clinicians (23 physicians, 10 nurse practitioners) led the 66 SIT meetings (39 SIT-1 and 27 SIT-2 or subsequent SIT meetings). Ten percent of meetings were

attended by ICU clinicians (five attending physicians, three house officers) and SIT palliative care specialists. Demographic characteristics of patients and surrogates are shown in Table 1; clinician characteristics are shown in Table 2 (12). Table 3 shows the content and implementation of SIT

meeting protocols. An illustrative discussion drawn from a SIT-1 meeting transcript is available in the online supplement.

Qualitative analysis identified a repertoire of surrogate responses to information about the patient’s illness and

Table 1. Characteristics of Patient and Surrogates

	Patients	Surrogates
N	43	51
Sex, M, n (%)	21 (49)	14 (27)
Age, yr, mean \pm SD	57 \pm 18	54 \pm 13
Race, n (%)		
Black	12 (28)	13 (25)
White	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, n (%)		
Hispanic or Latino	3 (7)	6 (12)
Not Hispanic or Latino	40 (93)	45 (88)
Unavailable	0 (0)	0 (0)
Religion, n (%)		
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, n (%)		
Duke University	5 (12)	6 (12)
University of North Carolina, Chapel Hill	14 (33)	17 (33)
Mt. Sinai Medical Center	16 (37)	18 (35)
Durham Regional	8 (19)	10 (20)
APACHE II score at enrollment, mean \pm SD	26 \pm 5	
Predicted 1-yr mortality, %, mean \pm SD*	57 \pm 22	
Died in hospital	16 (37)	
Decision-maker status, n (%)		
Primary surrogate		41
Additional decision-maker		10
Relation to patient, n (%)		
Child >18 yr old		15 (30)
Parent		10 (20)
Sibling		5 (10)
Spouse/partner		18 (35)
Other		3 (6)
Education, n (%)		
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, n (%)		
Employed		26 (51)
Unemployed (not disabled)		4 (8)
Homemaker		2 (4)
Retired		15 (29)
Disabled		3 (6)
Student		1 (2)

Definition of abbreviation: APACHE = Acute Physiology and Chronic Health Evaluation.

*Based on Provent predictive model (2).

Table 2. Characteristics of Clinicians

N	31
Sex, M, n (%)	10 (30)
Age, yr, mean \pm SD	46 \pm 10
Race, n (%)	
Black	1
White	29
Asian	1
American Indian/Alaskan Native	0
Other	0
Unavailable	0
Ethnicity, n (%)	
Hispanic or Latino	1 (3)
Not Hispanic or Latino	27 (87)
Unavailable	3 (10)
Religion, n (%)	
Catholic	4 (13)
Protestant	9 (29)
Jewish	7 (23)
Muslim	0 (0)
Other/none	10 (32)
Unavailable	1 (3)
Site, n (%)	
Duke University	6 (19)
University of North Carolina, Chapel Hill	4 (3)
Mt. Sinai Medical Center	17 (55)
Durham Regional	7 (23)
Profession, n (%)	
Physician	19 (61)
Nurse practitioner	12 (39)
Experience, n (%)	
Years since graduation, mean \pm SD, MD/RN	17 \pm 8.2/19 \pm 13.2
Years palliative care practice, mean \pm SD, MD/RN	5.3 \pm 4.8/6.6 \pm 4.4
Loved one had ICU treatment, n (%)	14 (45)

Definition of abbreviation: ICU = intensive care unit.

prognosis that we grouped into six main categories (Table 4): (1) receptivity, (2) deflection/rejection, (3) emotion, (4) characterization of patient, (5) consideration of surrogate role, and (6) mobilization of support. Diverse categories were represented in responses of the same surrogate within the same meeting, and responses of some families were dynamic across multiple SIT meetings. Illustrative passages are set forth below and in Tables E1 and E2 in the online supplement.

Receptivity

Although information about the condition and prognosis of chronically critically ill patients in this study was often disquieting, many surrogates seemed open and receptive to this information. Of the 43 families included in this analysis, surrogates in 37 (86%) expressed such receptivity, and passages reflecting receptivity were found in 83% (55 of 66) of SIT meetings. Families and clinicians acknowledged uncertainty about the patient's future course, while also valuing knowledge of prognosis as a basis

for informed, patient-focused, decision-making. Some surrogates took an active approach, affirmatively seeking answers rather than passively accepting information. For example, the son of a chronically critically ill woman said,

I would like . . . to get a better understanding in terms of the stats, you know, if someone was saying, you know, she has a 40% chance or she has a 50% chance. I mean, that . . . I don't know, for some people, it may be . . . but to me, just it would be easier.

Yet many expressed the pain of hearing inauspicious information, even as they pursued it. As a patient's mother said,

I don't want those answers, do you know what I mean? . . . But I . . . I need to know them, but I don't want them. It's kinda shitty [deep breath/sigh].

While clearly acknowledging that the patient's prognosis was poor, some surrogates also signaled their intention to

maintain hope for a more favorable outcome. Others who were faced with a patient's impending demise accepted the death as unavoidable, but sought control over timing or circumstances.

Deflection/Rejection

Discussion of unfavorable outcomes was deflected or even rejected by surrogates in 25 families (58%). Some seemed to trust their own judgment in place of the information that was shared. These judgments were based on current observations of the patient, or past experiences with the patient or others, or their own online or other research. Many surrogates invoked a "higher power" as paramount in determining the patient's outcome, taking precedence over science, medicine, or the judgment of any clinician. A patient's daughter said,

I thank you all for providing me with all the information and . . . I . . . just, at this point, . . . I know you all are doin' all that you can, but um, there is a higher power and . . . my mom's still fightin' and that one in three chance, or that one in ten chance, those chances are given. I don't . . . I don't retain it. I won't . . . I won't receive it at this point.

For some surrogates, responses framed in religious terms or references to miracles reflected a different explanatory model of illness/recovery than the standard biomedical model. A small number of surrogates expressed or implied distrust of the ICU team, including a concern that clinicians sought to limit treatment to reduce use of costly intensive therapies, or a suggestion that the team itself was to blame for the poor prognosis. A patient's husband said,

How long is it gonna be before everybody gives up and says, "Sorry, there's nothin' more we can do." What do you do? . . . When do you reach that point? . . . I know medicine is expensive uh . . . She's human, you know? . . . And uh, there's a dollars and cents mechanism for everything, you know. You know, Lord, I've had a company all my years and we made money, now we're broke, we made money, now we're broke and so on'n'so forth, but I never gave up.

Although most patients had been ventilated for a period of time far beyond the average duration of mechanical ventilation, it was common for surrogates to consider even general discussion of expected outcomes to be premature. As some put it, surrogates thought it was "too soon to give up." None

Table 3. Implementation of SIT Meeting Protocols

	Meetings in Which Covered [n (%)]
Topics at SIT-1 meeting	
Introduction of all participants	39 (100)
Patient's condition (family stated understanding first)	39 (100)
Patient's prognosis (family stated understanding first)	33 (85)
Alternatives to continued intensive care therapy	19 (49)
Care settings for chronically critically ill patients	22 (56)
Patient (oral or written) advance directive (if any)	22 (56)
Family summarized discussion	26 (67)
Family's understanding of patient's values/goals/preferences	35 (90)
Plan for follow-up with ICU team	26 (67)
Plan for follow-up with SIT clinicians	25 (64)
Topics at SIT-2 meeting	
Introduction of all participants	27 (100)
Patient's course/condition (family stated understanding first)	27 (100)
Patient's prognosis (family stated understanding first)	26 (96)
Alternatives to continued intensive care therapy	13 (48)
Likely discharge options (if patient survives)	18 (67)
Patient (oral or written) advance directive (if any)	10 (37)
Family summarized discussion	19 (70)
Patient's likely care needs	20 (74)
Family's understanding of patient's values/goals/preferences	22 (82)
Plan for follow-up with responsible MD	19 (70)
Plan for follow-up with SIT clinicians	10 (37)

Definition of abbreviations: ICU = intensive care unit; SIT = Supportive Information Team.

shared an understanding of clinical milestones, such as placement of tracheotomy. Some expressed resentment or anger about being “rushed” or “pressured” to decide about continuation or limitation of intensive care. Whereas the SIT clinicians sought to discuss overall, long-term prospects, many surrogates seemed to prefer to focus on isolated, day-to-day developments, such as individual laboratory values or ventilator settings. As a physician began speaking of the patient having had “a pretty hard time of it,” and suggesting the value of “stepping back” to “look at the big picture,” a patient’s sister responded:

Well, it’s like I told the doctor last night, I’m thankful for all the little progresses he’s made.

Some surrogates asserted themselves as optimistic, “positive,” individuals regardless of circumstances. Many referred to unique attributes of their loved one that would allow this patient to overcome poor odds. Characterization of the patient as “a fighter” throughout life and against the illness, with unusual strength and “will to live,” was most common. As one patient’s mother said,

I’ll tell you, that’s one fighter that’s layin’ in that bed. . . . If we all had that fight in us,

there’s no tellin’ what we could do in life. You know? So . . . but that’s why we gotta fight . . . fight on this side for him, too.

Other surrogates more directly rejected biomedical evidence or statistics as a basis for prognostication and decision-making about any individual. In the words of a patient’s sister:

I’m just sayin’, I understand what you’re sayin’. And I’m not bein’ combative. . . . I’m sayin’ that statistics and people are different.

For these surrogates, instinct, intuition, and even emotion seemed to deserve greater weight than science and logic in predicting the patient’s outcome and shaping appropriate goals of treatment. When asked whether it would be helpful to hear information about clinicians’ expectations for the future course of the patient’s illness, a small number of surrogates openly stated a preference not to receive such information, or shifted the discussion to another topic, as in the following exchange:

SIT MD: Would it be helpful to see or hear some numbers from the intensive care doctor?

MOTHER: Eh [frustrated sigh] you know, my answer to that is . . . And I would usually

say yes to that. . . . But I used to . . . do some case management . . . in a pediatric ICU. . . . We did a lot of um, left, hypo-plastics hearts. And one out of the four would die. . . . Statistically, one out of the four . . . that’s the national statistics . . . And they never quoted those statistics, period. And they wouldn’t let you quote those statistics because what ends up happenin’ is, most of the time, “It’s not gonna be . . . I . . . I’m gonna be the three.” “I’m not gonna be the fourth.” . . . And [clap] I . . . I want to continue to have good hope . . . in my child. . . . Now, if you’ve got really super statistics, maybe, but right now, I don’t want to go with the statistics.

Emotion

A range of emotions emerged from families. Of 43 participating in 66 meetings we studied, 40 (93%) families in 58 (88%) meetings conveyed emotional responses when presented with prognostic information. Some responded to discussion of adverse developments or expectations with anger directed at various targets. For example, a patient’s sister retorted:

Never once was it ever explained to me that it would be a life-changing process . . . But you know what? [voice breaks with tears] I really have a problem with them putting that shit on her in the first place, because see? I was here the whole day and she didn’t . . . need to be intubated. And then, when I come in the next morning, they intubate her. They said, “Oh, because she was spitting and she didn’t seem like she was breathing . . . she was gasping her breath quietly . . .” you know. . . . Who made that damn decision? Nobody called me. . . . I never signed off on that shit. And now you’re telling me that it could be something that’s indefinite?!

More often, surrogates showing emotion evidenced their sadness and grief, explicitly or through crying. One said:

Being a mother [tears start—7-s silence] you certainly don’t want to um, accept that there is nothin’ else you can do. . . . I love him more than anything in the world. [sobbing] . . . I just don’t know if I can . . . I can’t . . . It’s just . . . the hardest thing. [20 s crying softly] I guess, it’s being a mother and it doesn’t matter how old they get, they’ll always be your child and your baby, in your heart.

Meetings in this study also revealed the use of humor, which often seemed strained,

Table 4. Typology of Surrogate Responses with Definitions and Frequencies

Surrogate Response	Definition	Frequency of Response*			
		By Family [†] (n = 43) [n (%)]	By Meeting		
			SIT-1 (n = 39)	SIT-2 [‡] (n = 27)	All (n = 66) [n (%)]
Receptivity	Openness to clinical information, including the possibility of an unfavorable prognosis	37 (86)	34	21	55 (83)
Deflection/rejection	Avoidance, disbelief, use of an alternative explanatory model	25 (58)	22	11	33 (50)
Emotion	Comments (or audible behavior, such as crying) on or reflecting emotional state	40 (93)	36	22	58 (88)
Characterization of patient	Perspective on patient's unique personhood or surrogate's special relationship with patient	36 (84)	31	16	47 (71)
Consideration of surrogate role	Personally taking stock of one's responsibilities, burdens and/or conflicts as a surrogate decision-maker	40 (93)	36	22	58 (88)
Mobilization of support	Looking to family, friends, faith, clinicians, and patient as sources of support and guidance	33 (77)	31	15	46 (70)

Definition of abbreviation: SIT = Supportive Information Team.

*At least one response (passage of text) within category.

[†]Any surrogate within family in any SIT meeting.

[‡]Includes SIT-2 (n = 21) and subsequent SIT meetings (n = 6).

by surrogates hearing distressing news about loved ones. Some surrogates became silent, perhaps implying that the emotional impact of the information was strong enough to delay a verbal response.

Characterization of Patient

Surrogates in 36 of 43 families (84%) spoke of attributes, accomplishments, or aspirations that characterized the patient as a person. These comments extended beyond capacities, such as strength and determination that would enable the patient to overcome odds against recovery, and beyond the patient's specific preferences with regard to life-support or end-of-life care. Typically, surrogates looked back across the patient's life before the illness, providing a broader, deeper sense of the personhood and value of the patient as an individual. Patients were often described in terms of relationships with others (i.e., ways that the patient interacted with and was perceived by family and friends were windows into the patient's identity). As illustrated in the following passage in which a mother speaks of her chronically critically ill daughter, discussion of the surrogate's own relationship with the patient conveyed not only the patient's unique qualities but also the significance of this type of narrative as a mechanism for surrogates to find

meaning and comfort in the face of grief and loss:

We got along, you fight, you watch television, you eat, you go to the store. You know, you just live your life. . . . Then all of a sudden, that's just ripped out from under you . . . She was an adorable little one. . . . She was tiny, with bright red curls. . . . Always in trouble. Always doing horrible things around the house. . . . The older girl was the good girl, the blond, the pretty one. This was little chubby, flaming red hair. . . . Her first report card, she comes home, she had a D in art. . . . I said, "You got a D in art!" She said, "That means delightful." . . . That was her. . . . So full of life. . . . She had a million friends. . . . Got an award for best actress in community theater . . . But that was her. . . . She was, you know, just fun. We had a thousand parties. She collected Santa Clauses. There are 120 Santa Clauses in my garage. I don't know what to do with 'em. . . . But that's her. . . . And to see her laying quiet and not talking? . . . It's very hard. She was a life force. . . . Halloween parties, costume parties. They were all her.

Consideration of Surrogate Role

Surrogates' comments reflected their awareness of the demands and the import of their decision-making role. Surrogates in

93% (40 of 43) of families in this sample spoke in terms that evidenced concern regarding this role. Some expressed feelings of burden and weariness as surrogates, especially after a series of difficult decisions over a prolonged hospitalization. Weighing use of intensive care therapies for ongoing critical illness, surrogates struggled to integrate information from various clinicians that, to some, seemed fragmented or inconsistent. They also struggled with a sense that their decisions, rather than the underlying critical illness, would primarily determine the patient's outcome. Thus, some surrogates characterized a decision to limit life support as an affirmative action on their part to "kill," "starve," or otherwise harm the patient, even though the medical team advised that the patient was deteriorating despite this therapy. Surrogates spoke of the guilt they would feel in the aftermath. Yet they also expressed concern that continuation of intensive care was causing patient suffering, for which they felt responsible. As the son of one patient said:

A friend o' mine told me this weekend, he said, "Don't be selfish you know and try and keep Mom forever and ever" . . . I don't want to see her suffer . . . so . . . like I told the doctor, I said, "I don't want to see [stammering], I don't want to come

visiting her and just lookin' at her and, you know, on a vent." They told me everything and they said, "We could give her a trach" And I said, "Well, you know, I don't think she ever wanted to have a trach. . . . She wouldn't be able to talk," And they gave me . . . all the choices and all the precautions, too. . . . But uh, you know, you want some kinda quality of life, even though we can do extraordinary things and extraordinary measures . . . it's still . . . you want to be able to talk to somebody. You want to be able to take 'em to the park and . . . do things like that. . . . I mean, do I want to put her in a cryogenic chamber or You know? I think that you can't be that selfish a person, if they're suffering.

Conflict within the family about appropriate goals for the patient's care, particularly conflict between the surrogate and other family members, added burden and complexity to the role of surrogates. A patient's friend, who was his health care proxy, spoke of

struggling with his mom. . . . She has a different goal in mind. . . . I think her goal is, "I don't care what, I just want my son alive." . . . So, the reality of what that could mean in the end, when I have to say, "But he wouldn't want this," and she's sort of thinking, "But I'm his mother, so I don't care." [chuckle] You know? If his mother said, "Well no, I want this," or, "I want that." You know, what . . . is my role really, truly to be his voice, regardless? If this is one of those things where . . . there's clearly a huge divide there . . . in what he would want and what she wants. . . . Hoping that we don't get to that.

One definition of the surrogate's role that emerged from surrogates' comments in SIT meetings was to advocate aggressively and unequivocally for, not merely to weigh, the use of intensive care therapies. For most surrogates, however, the self-defined role was to give consideration to potential risks and benefits of treatment in accordance with the patient's specific preferences or broader values. Surrogates also seemed to believe that it was their responsibility to act in the patient's best interest. A patient's sister explained in her first meeting: "My whole thing is just to go through this process and try to be as informed as possible . . . so that I can relate it to my family and make the best decisions. . . ." In a later meeting, she commented,

What I've been doing all this time . . . is trying to advocate for her and what would be in her best interest and how I believe that she would want.

Some surrogates spoke of a more passive role, deferring authority over the decision-making to God. As a patient's mother said:

I'm not one who believes in saying, "Take him off the respirator." . . . I . . . that's not the way I believe. . . . And that is probably not something I'll ever do. . . . It'll basically come down to . . . him and . . . Well, him and God. . . . I'm just not . . . I don't think it's my place to make that decision. That's my opinion. That's the way I feel. So, I don't think that's ever going to be something I'm going to be able to do. I mean, it . . . that's me. . . . Who's to say when you're supposed to have your last breath? I don't think there's any one designated person that makes that decision.

Mobilization of Support

Facing concerns about the patient's future and their own role, surrogates looked to various sources for support. Although other family members complicated the situation for some, many surrogates marshaled emotional and practical support from their families and friends. Some surrogates spoke positively of support from members of the ICU team. Patients themselves were part of mutually supportive relationships with surrogates in some instances. Most often, surrogates relied on their religious faith and community. A patient's wife spoke of support as follows:

We have a wonderful church family. . . . They call and they check on us every day. . . . My pastor calls me just about every day . . . you know, church members, family members, they have been very supportive. . . . Financially and just in any other way. . . . My girls are back at home. We have two daughters, ages 20 and 13. . . . So my 20-year-old is kinda like in charge. And uh, you know, they get up and they get dressed and they go to school . . . and they basically, you know, handlin' things around the house. And my dad lives right next door. . . . So he's there to watch over things. But family members, they cook. . . . On Sundays, they tell my girls, "Come on down to the house and get you something to eat." They cook big meals and . . . and I don't have to worry about . . . I don't have to really worry about

them at home . . . goin' without . . . because there's family there who is very, very supportive and But I . . . but I just . . . I just attribute all of my strength . . . to God.

Overall, surrogates in 77% (33 of 43) of families spoke about one or more sources of support as they sought to cope with their loved one's illness and with their responsibilities as the decision-making surrogate.

Multiple Types of Responses by a Single Surrogate

Although our analysis identified distinct types of surrogate responses, we found that, almost universally, surrogates responded in more than one way, within or across SIT meetings. In fact, as shown in Table 5, all but one of the six major types of responses we described were found within the same meeting in one-third of the SIT meetings we analyzed. A surrogate might be receptive to or solicit information about the patient's expected outcome, while expressing grief and looking to religious faith for strength to face a grim prognosis. Some surrogates responded in antithetical ways during the course of one meeting, or evolved from one type of response to a contrasting type over multiple meetings. The direction of these changes was not uniform, that is, a surrogate might begin by asking about the patient's prognosis but then deflect distressing information, or initially reject prognostication by the clinician while ultimately soliciting, accepting, and even expressing appreciation for it. We found expressions of receptivity and resistance to information by surrogates in half (19 of 39) the families during SIT-1

Table 5. Single and Multiple Categories of Surrogate Responses in SIT Meetings

Number of Main Response Categories in Meeting	Number (%) of Meetings
0	1 (2.0)
1	2 (3.0)
2	3 (4.5)
3	5 (7.6)
4	17 (25.8)
5	22 (33.3)
6	16 (24.2)
Total	66

Definition of abbreviation: SIT = Supportive Information Team.

meetings and a third (9 of 27) during SIT-2 or subsequent SIT meetings.

“Member checking” involved eight randomly selected family participants in the intervention group and 14 SIT clinicians (eight physicians, six nurse practitioners). Family members and clinicians at each study site affirmed that the analytic framework included and was limited to representative family responses.

Discussion

Surrogates and clinicians agree that information about patients’ chronic critical illness and clinicians’ expectations for survival, ventilator liberation, and cognitive and functional outcomes is relevant and important for decision-making about continuation of intensive care (8, 10). In this study, observation of audio-recorded family meetings opened a new window into surrogates’ responses to such information as clinical events unfolded in real time. Our analysis supported a typology of six dominant and distinct responses by surrogates, but also showed that individual surrogates often respond in multiple ways that may reinforce their capacity to integrate and act on information, or reflect ambivalence and internal conflict that complicate their decision-making role.

In prior studies, qualitative analysis of ICU family meetings has focused on communication by critical care physicians and their responses to concerns and emotions expressed by the family (21–23). Other studies were based on structured interviews of surrogates in which research staff inquired about responses to information from ICU clinicians in meetings that were not directly observed (11, 24–26). Our study illuminates patterns of responses by patient surrogates to information in the direct light of real-time recording, and in the shadow of ongoing dependence of a loved one on intensive care after acute critical illness. Recognition of themes that tend to manifest in surrogates’ verbal responses to clinicians, and of the importance of attention to the emotional subtext of a clinician–family meeting, can help ensure that discussions meet surrogates’ needs and that decision-making reflects the medical realities and the patient’s values and preferences. The framework emerging from this study can also guide educators and investigators as

well as clinicians toward communication approaches that are most likely to achieve these important goals.

Whereas physicians often tend to dominate discussions with families and focus on delivering information, our findings align with previous research and recommendations emphasizing fuller opportunities for families to speak while clinicians listen carefully and empathically (17, 22). As they listen, clinicians can focus on family comments, anticipate and recognize statements within the range of expected responses in similar situations, consider the ways in which such responses may reflect strategies for family coping with psychological distress, and formulate more tailored approaches. Explicit expressions of empathy, such as “It sounds like the role of making decisions for your loved one is weighing heavily on you,” or, “It must be difficult for you to hear that the ICU team is worried about the future for the person you love so much,” or “I wish the team was more optimistic about what is likely to happen,” (22) are generally helpful in modulating emotions so that surrogates are better able to absorb and act on information.

What families and other surrogates hear, absorb, and use for decision-making is influenced at least as much by their own distinctive psychology as their interpersonal relationships with the patient, family members, and health care team. This may be especially true when the emotional tensions and exhaustion from a loved one’s illness continue over a prolonged period, as with chronic critical illness. Adding further complexity, our findings indicate that the same surrogate may respond in different ways in a single discussion, including responses that may superficially seem inconsistent, such as receptivity to information together with deflection of it. Like patients struggling to come to terms with an unfavorable or uncertain prognosis, surrogates may also “swing on a pendulum” of prognostic awareness (27), rather than integrate the information more consistently. Some surrogates are aware of their own ambivalence toward prognostic information, although they find it difficult to resolve the internal tension (11). Surrogates also have their own needs, which potentially shift attention between the patients and themselves.

Our findings should be interpreted in light of the study’s limitations. It is possible that surrogates who declined to be audio-

recorded are different from those we recorded. In addition, all participants in this study were among those who consented to participate in the larger randomized trial, in which the overall consent rate was 69.9%. Although palliative care clinicians led the meetings conducted in this study, they did not provide full palliative care consultations and may have approached these content-guided meetings differently than in their usual practice; surrogates’ responses in the context of such consultations might be different from those in SIT meetings. Surrogate responses to clinicians who are not palliative care specialists might also be different. Reported frequencies and proportions should be interpreted with caution in this qualitative study. Although the study comprised four sites, they were in two geographic regions. However, our study has important strengths. First, generalizability of our findings is enhanced by the diverse composition of our cohort. Second, thematic saturation was achieved during the time period of this study (19). Finally, we drew on the expertise of an inter-professional team to develop and refine the coding framework through a rigorous process, required agreement among multiple coders, and conducted “member checking” (19) to confirm our analytic framework.

Conclusions

Qualitative analysis of real-time, content-guided, communications between palliative care specialists and families of the chronically critically ill has identified a spectrum of responses by family surrogates to information about the condition and prognosis of patients, ranging from receptivity to deflection or rejection, and mobilization of support. Recognition of these themes may help all clinicians better communicate their support to patients and families facing chronic critical illness, and guide the development and evaluation of strategies and interventions to support surrogates caring for a loved one in the ICU. ■

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