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“It Hurts To Know...And It Helps”: Exploring How Surrogates in the ICU Cope with Prognostic Information

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Abstract

Background: Surrogates of critically ill patients in the intensive care unit (ICU) want honest prognostic information, but they also want to hear good news. There has been little examination of how surrogates navigate these dual needs or how clinicians should respond.

Objective: The aim of this study was explore how surrogates in the ICU experience and cope with prognostic information and describe their recommendations for clinicians.

Methods: We conducted a qualitative interview study with 30 surrogates facing life-sustaining treatment decisions in five ICUs in Pittsburgh, Pennsylvania. In-depth, semi-structured interviews with surrogates in the ICU focused on general experiences, emotional needs, informational needs, and recommendations for clinicians. We inductively analyzed transcripts for key themes using constant comparative methods.

Results: Surrogates experience a tension between wanting to know what to expect and needing to remain hopeful. This tension underlies their experience receiving prognostic information and may lead to behaviors that allow continued hope in the face of bad news, including: 1) focusing on small details rather than the big picture, 2) relying on gut instincts or personal beliefs about the patient, 3) seeking more positive prognostic information from other sources, and, for a minority, 4) avoiding or disbelieving prognostic information. Surrogates emphasize the importance of frequent communication and call on physicians to gently help them prepare for the worst *and* hope for the best.

Conclusions: Surrogates in the ICU experience conflicting emotional and informational needs. They describe behaviors that give the appearance of avoiding bad news while simultaneously asking physicians to help them cope with prognostic information.

Introduction

FAMILY MEMBERS FACING DECISIONS as surrogates for a critically ill loved one in the intensive care unit (ICU) report that they want honest prognostic information from physicians.¹⁻³ In one recent study, 93% of surrogates felt that avoiding discussions about prognosis was an unacceptable way to maintain hope,¹ and surrogate uncertainty about prognosis has been described as a key factor associated with a negative experience.⁴ Professional guidelines, supported by a growing body of literature, emphasize the importance of providing timely, accurate, and understandable prognostic information to surrogates.^{5,6}

At the same time, family members find it difficult to hear bad news and may respond in ways that undercut their desire

to hear prognostic information.⁷⁻⁹ Some surrogates ask not to be given bad news. Others accept prognostic information yet retain alternate beliefs, for example, by remaining optimistic that a patient will recover in the face of a grim outlook.¹⁰⁻¹²

Communication theorists have noted that uncertainty about prognosis serves dual roles in medical discussions, as it is associated with positive as well as negative emotions.¹³ Patients and families may feel conflicted in their desire for prognostic information when they fear bad news and a loss of hope. Tension between cognitive and emotional needs may be heightened near the end of life, when the likelihood of receiving bad news is high and hope plays a key therapeutic role.^{14,15} Ambivalence toward receiving prognostic information and conflicting desires for doctors to be both honest *and*

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optimistic have been described among patients with serious illness.¹⁶⁻¹⁸ To date there has been little exploration of how surrogates in the ICU experience and cope with prognostic information, nor have prior reports included surrogates' suggestions about how physicians should communicate with families when cognitive and emotional needs are in conflict.

Interested in these questions, we sought to explore how surrogates of critically ill patients in the ICU grapple with prognostic information. In this analysis, we describe the tension between wanting to know what to expect and needing to maintain hope, associated coping strategies, and recommendations for physicians.

Methods

Design, setting, and participants

We conducted semi-structured, in-depth interviews with surrogates from five ICUs (three medical, one mixed medical-surgical, one cardiovascular) at two hospitals (one academic tertiary care center and one academically affiliated community hospital) in Pittsburgh, Pennsylvania. We recruited participants between December 2010 and September 2011. We included adult surrogates (18 years or older) who were able to complete a 45-minute interview in English and self-identified as a primary decision-maker for an eligible patient. Although decisions are often shared among multiple family members, for the purposes of this study we included only one surrogate per patient to maximize our ability to capture a diversity of surrogate experiences. We excluded surrogates who did not self-identify as African American or Caucasian because these interviews were conducted as part of an initial observational study designed to characterize and compare these groups' decision-making experiences. Eligible patients were incapacitated adults (18 years or older) for whom the attending physician predicted a 50% or greater chance of death or long-term disability and for whom there had been an initial discussion about goals of care or life support decisions. We excluded patients who were participating in a parallel study in order to minimize participant burden. Study procedures have been described previously, although no previous report from this dataset has described surrogates' informational and emotional needs.¹⁹

Enrollment

Research staff screened for eligible participants through daily contact with ICU staff. We confirmed eligibility and obtained permission to approach surrogates from the ICU attending physician. We approached only those eligible surrogates who agreed to hear about the research study when asked by an ICU nurse, an extra step added to protect surrogates from feeling "cold-called" by research staff. All surrogates provided written consent and received a \$25 gift card. The Institutional Review Board at the University of Pittsburgh approved all study procedures.

Interviews

The study interviewer (GT) received extensive training in in-depth interviewing techniques and qualitative data collection.²⁰ Interviews were conducted in private locations and lasted an average of 51 minutes (range 14 to 100 minutes). The interview guide began with general questions about

participants' experiences as surrogate decision-makers, then probed about barriers and sources of support, role perception, informational needs, and values. In addition, participants were asked to make recommendations to the hospital, doctors, or staff to improve their experience. (See Appendix for complete interview guide. Appendix is available online at www.liebertonline.com/jpm) Surrogates completed a brief demographic questionnaire after each interview. We collected data until thematic saturation was reached, meaning no new themes emerged from additional interviews.^{21,22}

Interviews were audiorecorded and transcribed verbatim. A multidisciplinary team (YS, GT, DD, and MC) used constant comparative methods to inductively develop and refine a coding framework. We conducted initial coding individually on a subset of transcripts and then held team meetings to compare and refine emerging themes, developing our final coding framework through this iterative process. Two authors (YS and GT) applied this framework to all transcripts, resolving all disagreements through discussion and consensus.

Results

Of 187 participants screened, 45 were eligible and 30 enrolled. The enrollment rate was 67% (see Fig. 1). Surrogates were predominantly Caucasian (87%), female (67%), and the spouse/partner (43%) or adult child (37%) of the patient. Patients had been in the ICU an average of 10 (\pm) days at the time of the interview; the inpatient mortality rate was 50% (see Table 1). We present data on the tension between wanting to know what to expect yet needing to maintain hope, associated coping strategies, and recommendations for physicians.

Surrogates experienced a tension between wanting to know what to expect yet needing to maintain hope

All participants reported wanting more information about their loved ones' treatments or prognoses. Many surrogates described this information as critically important to their decision making. As one daughter said, "The decisions that you have to make are quite difficult. And of course, when you make them, you want to feel like you have as much information as you can, so you can make the best decision." Several participants also commented that not knowing what to expect was emotionally difficult because they were unable to prepare for the future or feared the worst. As another daughter noted, "The unknown is the scariest part...just not knowing what she's gonna do."

The need to maintain hope was an equally salient theme. Most participants described feeling hopeful that their loved one would recover, even when they knew that chances were small of this happening. As one wife said, "We were given a slight glimmer of hope today from the doctor although he says...my husband, is as sick as it's possible for a person to be sick. And so it's a very, very small glimmer...but we're grabbing onto that and we're gonna hold on to it for a couple days." Others described hope as what made it possible for them to go on. As another participant said, "I can cope with it [her husband's critical illness] because...I know he's gonna come through it well."

For many surrogates the need to maintain hope conflicted with their desire for more information. This conflict was evident among participants who openly struggled during the

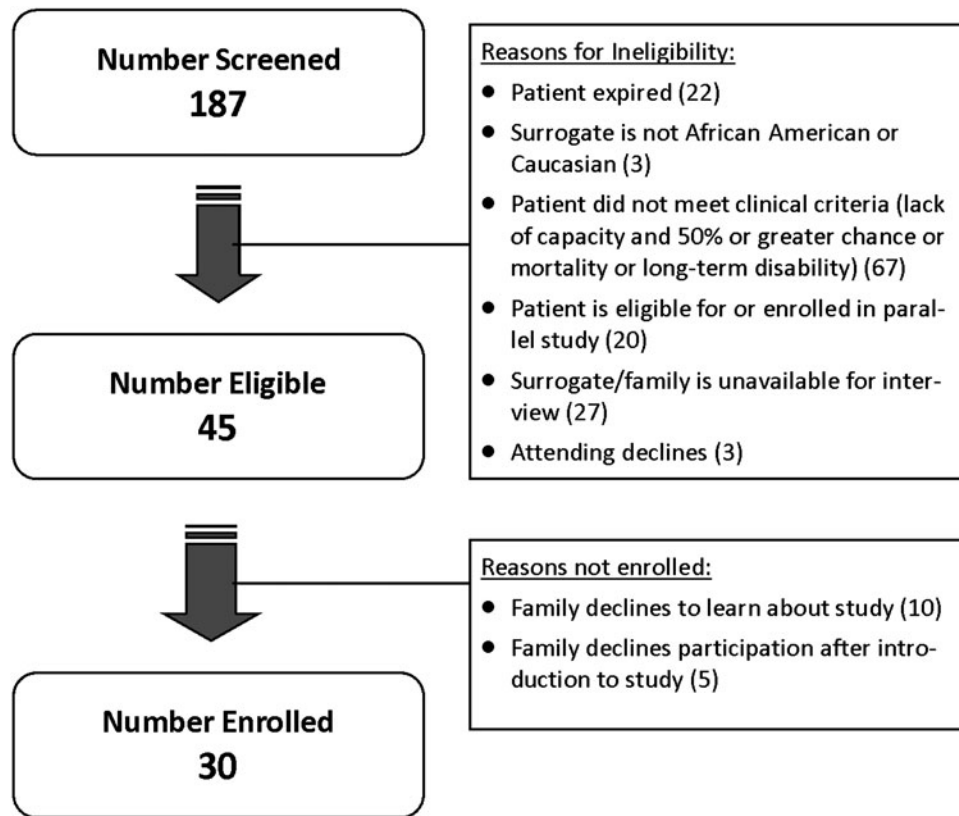


FIG. 1. Enrollment flow chart. (With kind permission from Springer Science & Business Media. See reference 19.)

interview with how they felt about receiving prognostic information. As one husband said, “They [physicians] do decide to give us some type of answer to give us some comfort. Or...if we don’t like to hear it, they still give it to us anyhow. Which I...I appreciate. Sometimes I do, sometimes I don’t...but I...I had to appreciate it.” Others described times when they were more or less able to deal with prognostic information, depending on their emotional state. As one daughter said, “There’s going to be days that I can absolutely handle the truth and other times that I might cry about it.” Participants noted that they wanted to know what to expect but found this information difficult to hear. As one wife said, “I was very well informed...they [physicians] were very straightforward. I felt like I got punched in the gut every day. You know, it was terrible. But I did have the facts I needed.” A minority admitted that they really only wanted to hear good news. As one son said, “We don’t wanna really hear anything else. Um...no news is good news right now.”

Surrogates employed four coping strategies to manage this tension

Participants described four behaviors that allowed them to remain hopeful in the face of bad news, as described below. Additional representative quotes for each behavior are included in Table 2.

Focusing on small details. Many participants described the importance of observing small changes in a loved one’s status. Some focused on clinical data such as urine output or respiratory rate; others noted more personal signs such as

whether a loved one was able to open her eyes or shake her head. As one mother said, “Just coming back to see her, you know, every couple minutes makes it easy to get through it...and seeing every little progress that she makes, even though small, it...helps to know that she’s doing okay.” Focusing on small details fulfilled a need for information and helped surrogates to maintain hope in the face of an overall poor prognosis.

Relying on gut instinct or personal beliefs about the patient. Several participants described access to unique knowledge about their loved one. As one husband said, “She shakes her head and a certain way she looks at you; you know if it’s a yes or a no, believe me. How does that saying go? She got daggers in her eyes—that means no. Somethin’ ‘bout it, the eyes are a li’l bit smiling—it’s a yes and I’m treasuring that, because she’s able to do this. She don’t listen to the doctors.” Gut instinct or personal beliefs about the patient superseded bad news from physicians and allowed these surrogates to remain hopeful.

Seeking information from other sources. Most participants described seeking prognostic information from sources beyond the ICU clinical team, including online references, other physicians, and family or friends with medical backgrounds or similar experiences. Surrogates described searching for outside confirmation of their loved one’s condition and for better news than they were hearing from the ICU team. As one mother said, “I would weigh with...pretty much what I’m told. And then, if I didn’t like the options, I would search out other options.”

TABLE 1. CHARACTERISTICS OF PARTICIPANTS

	Patients (n=30) N (%) or mean \pm SD	Surrogates (n=30) N (%) or mean \pm SD
Gender		
Male	16 (53)	10 (33)
Female	14 (47)	20 (67)
Race		
Caucasian/White	26 (87)	26 (87)
African American/Black	4 (13)	4 (13)
Age, years, mean (SD)	58 \pm 18	53 \pm 13
Relationship to patient		
Spouse/partner	–	13 (43)
Child	–	11 (37)
Sibling	–	1 (3)
Parent/Step-parent	–	4 (13)
Friend	–	1 (3)
Admission diagnosis		
Respiratory failure	17 (57)	–
Cardiac failure or shock	7 (23)	–
Neurologic failure	6 (20)	–
Site		
Academic tertiary care hospital	17 (57)	–
Academically affiliated Community hospital	13 (43)	–
Days in ICU	10 \pm 8 (range 1–35)	–
Died during this hospitalization	15 (50)	–
Highest level education		
Less than high school	–	2 (7)
High school diploma or GED	–	7 (23)
Some college	–	4 (13)
Completed college	–	7 (23)
1 or more years of post graduate	–	2 (7)
Graduate or professional degree	–	8 (27)
Annual household income		
>\$40,000	–	6 (20)
\geq \$40,000	–	22 (73)
Decline to answer	–	2 (7)
Religion affiliation		
Protestant Christian	–	16 (53)
Roman Catholic	–	8 (27)
Jewish	–	1 (3)
Buddhist	–	1 (3)
No religious affiliation	–	2 (7)
Other/No response	–	2 (7)
Importance of religion		
Very important	–	19 (63)
Somewhat important	–	8 (27)
Not important	–	2 (7)
No response	–	1 (3)
Has a living will ^a	9 (30)	–

^aAssessed via surrogate questionnaire.

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Avoiding or disbelieving prognostic information. A minority of participants openly described the inclination to avoid bad news. As one participant noted, “When things were the worst...I wasn’t coping...I didn’t want to deal with it, I didn’t want to hear it, I didn’t want to talk about it.” For some this meant avoiding doctors who were more pessimistic. For others it meant not asking for information that they did not want to hear or not believing information they had been given. One son described the tendency to avoid bad news as a common coping strategy: “Eight out of 10 people won’t ask. Or...won’t want to hear the truth and how bad it really is.”

Surrogates called on physicians to gently help them prepare for the worst and hope for the best

Despite feeling conflicted and employing coping strategies that gave the appearance of avoiding poor prognostic information, all participants emphasized the importance of communication with their loved ones’ physicians, which they described as vastly preferable to being left to wonder what was going on. As one daughter said, “The biggest thing we need is, probably, every day to hear from that doctor, ‘This is what’s going on.’ Truthfully, this is where we’re at. This is what our goal is. This is where we’re headed.” Many participants gave specific suggestions to clinicians about how to talk with families (see Table 3 for representative quotes). Overall, surrogates called on physicians to gently help them face bad news and prepare for the worst while allowing them to hope for the best. As one son said, “We’re ready for the worst expecting the best...although it hurts to know, and it’s...almost debilitating to even think about, and it makes you have an awful feeling in the pit of your stomach that you just don’t wanna know, but it’s something that I think...helps us make those decisions. It helps us grieve; it helps us get a better understanding of what’s going on...you know, it helps keep your mind straight.” Surrogates emphasized the importance of providing emotional support when giving bad news and called on physicians to be empathic and to ask about preferred communication styles, noting that different families had different preferences.

Discussion

In this analysis we highlight a common tension experienced by surrogate decision-makers for critically ill patients in the ICU: wanting to know what to expect yet needing to maintain hope that their loved one will survive. Whereas nearly all surrogates endorsed the importance of regular and honest communication, many participants described a conflicted relationship with prognostic information and expressed a desire for physicians to supportively engage them with reality.

These data increase our understanding of the complexity of needs among families in the ICU, who must simultaneously manage the cognitive and emotional aspects of the health threat to their loved one. Uncertainty about what to expect can induce anxiety,¹³ and information about prognosis and treatment options is critical to allow surrogates to share in decision making. Yet the distress associated with receiving bad news and a desire to maintain hope—shaped, in part, by the cultural context of the ICU²³—may lead to ambivalence about receiving such information.

Our data suggest that surrogates in the ICU grapple with how to accept prognostic information while preserving hope

TABLE 2. EXAMPLES OF STRATEGIES FOR COPING WITH COGNITIVE-EMOTIONAL TENSIONS

Strategy	Representative quotes
Focusing on small details	<i>I have been taking a lot of notes and I keep a... um... I try to keep track of a lot of his numbers like his... uh... kidney function and liver function, white blood count... uh, gas exchange numbers, things like that. And I try to be able to interpret what those mean. That helps me tell whether he's, you know, getting better or worse (patient's wife)</i> <i>... seeing the little bit of positive that's usually there, you know, like even though you're stuck on, maybe, "oh she didn't have a good day," they said, "yeah, but look at what she did, you know, she could open her eyes today."... I always hang on those little things. (patient's daughter)</i>
Relying on gut instinct or personal belief	<i>... they said that it looked pretty grim and it looked like he probably wasn't going to come off the ventilator and... tomorrow will be two weeks that he's been on the ventilator and I have pretty strong beliefs that he's going to beat all odds and prove the doctors wrong and he's gonna come off that ventilator. I believe it's going to happen. (patient's mother)</i> <i>After you go through a little more and more, you kinda realize... I mean, I know he's a strong human being, you know, he is very strong and... this is a setback, you know, for him. But he'll be okay in the end. I know that. So... I have faith in that. So, it kinda helps. (patient's wife)</i>
Seeking information from other sources	<i>... I went on my own, and I went online and found the plus sides of it. I did find three survivors of this. Not necessarily at this hospital, but, I think there's more information out there in the world, that would have been a big help. To say, "okay, we don't have any survivors, but there are three out there." (patient's wife)</i> <i>I check a lot of things out. You know, I take the information I have, I go ask more questions from people outside of this inner circle here, you know, to... just get a second check on... because, again, I work with some physicians and some nurses. Um... and I also do a lot of reading on the internet. (patient's sister)</i>
Avoiding or disbelieving prognostic information	<i>And I just... maybe it's avoidance. Maybe I don't want to know sometimes. And I don't wanna go to the computer and type in and see what could happen. (patient's wife)</i>

and call on physicians to help meet both needs. Consistent with other studies, participants did not view avoiding discussions of prognosis as an acceptable way to maintain hope.¹ Rather, they envisioned the role of physicians as not only providing prognostic information but helping families face

the news and its implications. Families had considerable insight into their emotional difficulty with hearing information and their tendency to "focus on the trees rather than the forest" or "continue asking for information until they got better news." They wanted doctors to attend to their coping

TABLE 3. COMMUNICATION RECOMMENDATIONS FOR CLINICIANS

Recommendation	Representative quote
Ask about preferred communication style	<i>... there's some doctors that don't like to set down and tell people they're gonna lose their loved one. There's some doctors that are... [short laugh]... that is hard as nails. They'll just look you right in the eye and say, "Hey, she's gone. She's leavin' ya." You know. Some people like them kinda doctors. I like for 'em to sneak up on me, you know what I'm sayin'? I like for 'em to say, "Hey let's break this to him a lil bit gently," you know. That's the only recommendations I could ever make to a hospital.... you gotta know the patient's people, to know how to talk to them also. There you go. Because if you don't know them, you might come outta there and say somethin' and he might come might slap you upside your head. (patient's husband)</i>
Be empathic	<i>... it's just basically, try to put yourself in their shoes, or, you know, in my shoes... it's not always an easy road, but give us the facts so we can make the best decisions possible, you know what I mean? Not that you can foretell the future, 'cause I wish somebody could have, or can... but just take those steps with us. I'm kind of like that person that I just want people to be real and on my level, and we're all the same kind of people and... you know what I mean? So... hopefully they never have to go through it, but if they do, just to figure out what they might want and do the same for people.... a hug... no, I don't want to hug most doctors... but... just to be there, in any way possible, I guess. (patient's daughter)</i>
Be honest	<i>They pulled us into a room and what I... some people might not like it... I did. I liked that they were candid, they were forward. Not heartless, but didn't b.s. us, they told us how it was. And I wanted that... I don't wanna get... don't give me false hope, be honest with me. (patient's daughter)</i> <i>I know some nurses who will... who will try and... you know, sweeten the deal and say that they're optimistic. And I don't want to hear those words come out of anybody's mouth unless they are optimistic. I don't want to... uh... I don't want to have my sister have false hope for something that might not be there. (patient's son)</i>
Acknowledge uncertainty	<i>I need to be prepared for whichever direction we're going. And even if that doctor doesn't know he can say today, "This is what I say today, but that can change tomorrow." Because then if you know things, you can at least go forward. Just sitting there not knowing is like, oh my gosh! (patient's daughter)</i> <i>Whatever that doctor's got, I want. I don't care if it's good, bad, or indifferent. If he just plain could look at me and say, "I don't know what's going on today." That's okay too. (patient's daughter)</i>

strategies in a way that helped them more effectively process information. This is likely to require complex interpretive, deliberative, and emotion-handling skills.²⁴ These communication techniques are rarely taught to physicians-in-training and may present a challenge for many doctors.^{25,26}

Acknowledging potential cognitive-emotional tension even after surrogates have asked for prognostic information, for example by saying "I know this information can be helpful but also difficult to hear," may help to open discussion about preferred communication styles and emotional needs. As a clinical situation worsens, redirecting families from hope for a cure to hope for other things, such as a good death, may also help surrogates to gently face reality.⁹ By recognizing avoidant coping behaviors as responses to a common tension, physicians may better support families who are struggling to balance informational and emotional needs. For example, a physician may respond to repeated questions about small clinical details by gently asking a family member how they are coping. Similarly, asking families where else they are looking for information about how their loved one is doing and what they have found may help to initiate discussion about surrogates' true concerns.

Additional work is needed to assess and improve physician communication skills in the areas we have described, as well as to determine the extent to which these techniques influence surrogate and patient outcomes.

Our study had strengths and weaknesses. By enrolling surrogates actively involved in decisions for a loved one in the ICU, we were able to elicit open responses about informational and emotional needs without the potential for recall bias inherent in retrospective studies. Conducting in-depth interviews until thematic saturation was reached allowed us to fully explore the diversity of responses to these tensions. However, our qualitative approach did not allow us to quantify or compare communication preferences. In addition, our sample was predominantly Caucasian and the majority of surrogates were female, highly educated, in a higher income bracket and religious, meaning we were unable to explore differences in responses between racial or ethnic groups and our findings may not generalize to more heterogeneous surrogate populations. Our inclusion criteria were based on a qualitative assessment of illness severity and may have led us to exclude some surrogates of critically ill patients who were not deemed to meet these criteria by their attending physician. Finally, our study was conducted at two hospitals in Pittsburgh; findings may not generalize to other regions.

In summary, this study adds depth to our understanding of how surrogates cope with receiving negative prognostic information and raises the possibility that fostering truly patient-centered decision making may require physicians to go beyond the role of information provider. Understanding the range of coping strategies and practicing recommended communication strategies provide a starting point for clinicians to navigate conflicting informational and emotional needs in discussions with families of critically ill patients.

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Author Disclosure Statement

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