



I Don't Want to Be the One Saying 'We Should Just Let Him Die': Intrapersonal Tensions Experienced by Surrogate Decision Makers in the ICU

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BACKGROUND: Although numerous studies have addressed external factors associated with difficulty in surrogate decision making, intrapersonal sources of tension are an important element of decision making that have received little attention.

OBJECTIVE: To characterize key intrapersonal tensions experienced by surrogate decision makers in the intensive care unit (ICU), and explore associated coping strategies.

DESIGN: Qualitative interview study.

PARTICIPANTS: Thirty surrogates from five ICUs at two hospitals in Pittsburgh, Pennsylvania, who were actively involved in making life-sustaining treatment decisions for a critically ill loved one.

APPROACH: We conducted in-depth, semi-structured interviews with surrogates, focused on intrapersonal tensions, role challenges, and coping strategies. We analyzed transcripts using constant comparative methods.

KEY RESULTS: Surrogates experience significant emotional conflict between the desire to act in accordance with their loved one's values and 1) not wanting to feel responsible for a loved one's death, 2) a desire to pursue any chance of recovery, and 3) the need to preserve family well-being. Associated coping strategies included 1) recalling previous discussions with a loved one, 2) sharing decisions with family members, 3) delaying or deferring decision making, 4) spiritual/religious practices, and 5) story-telling.

CONCLUSIONS: Surrogates' struggle to reconcile personal and family emotional needs with their loved ones' wishes, and utilize common coping strategies to combat intrapersonal tensions. These data suggest reasons surrogates may struggle to follow a strict substituted judgment standard. They also suggest ways clinicians may improve decision making, including attending to

surrogates' emotions, facilitating family decision making, and eliciting potential emotional conflicts and spiritual needs.

KEY WORDS: decision making; end of life care; ethics; intensive care.

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BACKGROUND

One in five Americans die in or shortly after discharge from an intensive care unit (ICU),¹ and the vast majority of these deaths are preceded by a decision to limit life-sustaining treatment. Because patients are most often too ill to participate, surrogates are asked to make choices based on what their loved one would want.^{2,3} Concerns have been raised about the extent to which current approaches to decision making place undue strain on families and lead to decisions that do not accurately reflect patient values.^{4–6} A recent systematic review found that at least one third of surrogates report negative emotional effects lasting months, and sometimes years, after making treatment decisions for others, including stress, guilt and doubt about whether they made the right choice.⁷

Research on surrogate distress has been primarily retrospective, asking families to reflect back on decisions made in the past.⁷ Studies designed to explore sources of difficulty in surrogate decision making have mainly examined external factors, such as uncertainty about prognosis or a loved one's preferences, poor communication or conflict with clinicians, or discomfort in the ICU environment.^{8–14} Interventions to improve surrogate decision making similarly focus on strategies to provide better prognostic information, values clarification, and surrogate-clinician communication.^{15–21} There has been little exploration of how family members grapple with intrapersonal

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tensions — meaning inner emotional conflicts²² — while making life or death choices for a critically ill loved one.

We interviewed family members actively involved in life-sustaining treatment decisions for a patient in the ICU, to better understand surrogates' emotional experiences and more closely examine the nature of the dilemma faced by families in the midst of decision making. In this analysis, we document three sources of intrapersonal tension, examine associated coping behaviors, and note relevant recommendations for clinicians.

METHODS

Study Design, Participants and Setting

We conducted in-depth, semi-structured interviews with surrogates between December, 2010 and September, 2011. Participants were recruited from five ICUs (three medical, one mixed medical-surgical, and one cardiovascular) at two hospitals (one academic tertiary care center and one academically-affiliated community hospital) in Pittsburgh, Pennsylvania.

Inclusion criteria for patients were age 18 years or older, lack of decision making capacity, and 50 % or greater chance of death or long-term disability, as determined by the attending physician. Because we were interested in the experience of surrogates actively facing decisions for their loved ones, we included only patients for whom there had been an initial physician–family discussion about goals of care or life-sustaining treatment decisions. Surrogates were included if they were 18 years or older, able to speak English and participate in a 45-minute interview, and self-identified as the primary decision maker for an eligible patient. We excluded surrogates who did not self-identify as African American or Caucasian, because these interviews were conducted as part of a larger study to characterize and compare these groups' decision making experiences. There was no intervention component to this study and we do not anticipate that the larger study design influenced qualitative responses. Although the responsibility for surrogate decision making is often shared between several individuals, we limited enrollment to one primary surrogate per patient, to minimize the possibility that our data would be unduly influenced by unique views held by multiple members of the same family. We additionally excluded surrogates who were already enrolled in a parallel research study, to minimize participants' burden.

The study coordinator identified eligible patients by screening daily in the ICUs. Before approaching potential surrogates, we confirmed patient eligibility and obtained permission from the primary attending physician. All surrogates provided written consent to participate in the study. Participants received a \$25 gift card. The institutional review board at the University of Pittsburgh approved all study procedures.

Data Collection

Surrogates completed a brief demographic survey and participated in a semi-structured interview. The interview guide was developed with input from all members of the study team and included open-ended questions about the experience of making decisions for a loved one in the ICU. Initial questions were designed to elicit surrogates' general experiences making decisions for their loved one. Subsequent questions focused on challenges or barriers, sources of support, perceived roles, and coping (see [online appendix](#) for complete interview guide). The interviewer received extensive training in gathering qualitative data and in-depth interviewing techniques.²³ The average interview length was 51 minutes (range 14–100 minutes). We refined interview probes as data collection progressed to explore emerging themes and enrolled subjects until thematic saturation was reached, meaning no new themes emerged from the data.²⁴

Qualitative Data Coding

Interviews were audio-recorded and transcribed. We used constant comparative methods to inductively develop and refine our coding framework.^{24,25} Four investigators from diverse backgrounds (YS, GT, DD, MC) performed initial line-by-line coding independently on a subset of transcripts. The coding team then met to compare emerging concepts and themes. We repeated this process on an additional subset of transcripts and refined our coding structure as concepts emerged. All investigators participated in development of the final coding framework through a series of team meetings. This framework was applied to all transcripts by two investigators (YS and GT) who met regularly to compare codes. All disagreements were resolved by team consensus. The kappa for the codes that comprise our main analysis was 0.98.

RESULTS

Of 187 screened participants, 45 surrogates were eligible and 30 were enrolled, for an enrollment rate of 67 %. Reasons for non-enrollment are shown in Fig. 1. The characteristics of participants are shown in Table 1. We present data on intrapersonal sources of tension and associated coping strategies.

Intrapersonal Tensions

When responding to questions about their perceived role, all participants described the importance of considering their loved ones’ values or acting in their interest. Some surrogates recalled prior conversations or pointed to advance-care planning documents as evidence of what their relatives would want. Many others had not discussed these issues specifically, but called on personal knowledge of their loved ones to decide what their wishes would be. As one daughter said, *“I have to make them [decisions] from my heart, knowing the kind of person that she is.”*

Surrogates also invoked three emotional needs that were often in conflict with making decisions purely according to the patient’s values and preferences: 1) not wanting to feel responsible for a loved one’s death, 2) a desire to pursue any chance of recovery, and 3) the need to preserve family well-being. Below we describe these

Table 1. Characteristics of Participants

	Patients (n=30)	Surrogates (n=30)
	N (%) or Mean ± SD	N (%) or Mean ± 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, yr, mean (SD)	58±18	53±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±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)
One or more years of post graduate	–	2 (7)
Graduate or professional degree	–	8 (27)
Annual Household Income		
Below \$40,000	–	6 (20)
≥ \$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*	9 (30)	–

*Assessed via surrogate questionnaire

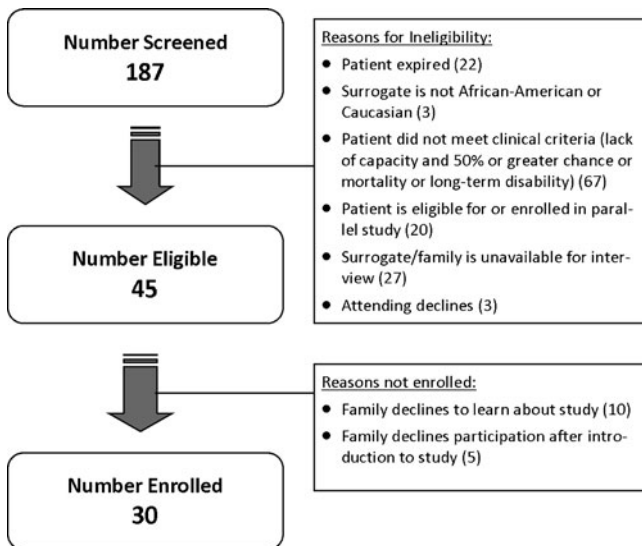


Figure 1. Enrollment flow chart.

salient sources of intrapersonal tension. Additional representative quotes are included in Textbox 1.

Textbox 1. Intrapersonal Tensions

Intrapersonal Tension	Representative Quotes
Responsibility for a loved one's death	<p>I've always dreaded being in a situation like this, where you do have to take responsibility for decisions you make about somebody else... and that somebody else is... it's not somebody else, it's my mother, someone I love, I hold dear... it's... I'm not sure, I'm not sure there's an easy way... it's just... it's tough, it's tough.</p> <p>You know, I basically, on day three, just laid him at God's feet and said, 'okay, take over. If you are going to take him home, take him home. You know, that's okay with me.' I was okay with that, but I didn't want it to be because I signed something, because I would have always lived with the 'what if's. What if? Did I make the right decision? Did I...? You know... and we have children, and I just... I didn't want it to be my decision, but if it were his time to go, I was okay with that.</p> <p>The easy ones are fine, I don't have a problem with them. It's them more difficult ones that make me uncomfortable . . . Like life and death - I don't want to have to choose his life or death. I don't even want to choose that he'd have to live in a nursing home for the rest of his life, 'cause that's not what he would want. . . . That would be a difficult, uncomfortable decision for me. But if it was saying he's not allowed to have ketchup anymore, I... I could handle that one, you know?</p> <p>I think we're both on the same path, especially now, it's just, um... you know, like... it's your mom, you want her around for... ever, if you could have her around forever. And she has um... some of her wishes are like, 'four days on the ventilator with no improvement...', -which there has been- I have to sign a consent to take her off. And whatever happens happens. But just knowing like, that I might be signing her death sentence, more or less, you know... that's what's hard. [voice breaking, starting to cry] And that's... and I know and I understand that she wouldn't want to live like that, so I am on the same path as her, but it's still like the emotional aspect of it.</p>
A chance of recovery	<p>You're... you want to give her a chance. And that's it, that's all. And that's why even now you...they talk about the trach and dialysis and things and you think, well, I'm not sure if she'd want that trach thing going on, but... why not give her a shot at it, a chance... I don't know. That's what I struggle with, that's the struggle</p> <p>I wanted to see if he would get any better over time... you know, if we gave it a little bit of time. It doesn't, right now at this point, it doesn't really look like he's going to. But, there's always that chance . . .</p> <p>while she wouldn't want long-term machines and things working for her and making her stay alive, things to save her life? Yeah, we wanted to do that.</p>
Family well-being	<p>And I have a son at home, too. He's sixteen. So it's kinda like... you're kinda pulled apart in two different ways, you know? 'Cause he needs you and then you need to be here. And, you know... he's frightened. So, it makes it harder . . . you know... not a great situation to be in, to be torn between two people.</p> <p>People questioning you. Family members... usually, you know... it's not like, I wouldn't say it's uncomfortable. But it just makes you kinda sit back and be like, okay, well, why are you doubting me, 'cause [patient] didn't doubt me, you know?</p> <p>I said when this happened, how terrified I... I would be... how terrified I would be to lose her and have her die. But I'm also terrified of, what if she lives? I mean, ultimately, what... at what emotional, physical, economic cost to the family? You know, what would... what would it be? And I know, without a doubt that the kids come first to her. So, in decisions going forward, I have to... what would she want for the kids? There's no question it's the kids.</p>

Responsibility for a Loved One’s Death. Many surrogates described emotional discomfort with making ‘life or death’ decisions as an important source of tension that sometimes made it difficult to act according to a loved one’s values. “I don’t want to have to choose his life or death,” one wife said. Several participants described withdrawing life-sustaining treatment in negative terms such as “pulling the plug,” or “giving up,” and many anticipated lasting psychological burdens associated with making this choice. As one mother explained “When you make a decision like that – to shut a machine off – that’s something you have to live with for the rest of your life. And you have to make sure that that was the right decision to make.” A minority of participants openly described conflict between their own emotional needs and a loved one’s wishes, and this tension seemed to worsen the burden of decision making. As one son said, “I know she wouldn’t want to go on the way she is now . . . I know she would want me to make this decision . . . to just take charge and just say ‘. . . that’s enough, just let her go’ . . . that might be the part that bothers me: that I’m kind of holding back . . . I gotta look at if I’m being selfish . . . it goes through my head every day.”

A Chance of Recovery. Most participants described a desire to pursue any chance of recovery as also influencing their decisions. As one son said, “My biggest fear would be to make the wrong decision, and the wrong decision for me would be to not give her a chance... to recover to get better.” Surrogates’ instinct to avoid death if possible was sometimes in conflict with their loved one’s preferences, and many noted that this tension also made decisions more difficult. As

a mother said, “She’s always said she wouldn’t want to live on a machine. But right now, I’m making the decision that it’s best for her to be on that machine because there’s a potential for her to come off of it... and everything.”

Family Wellbeing. The majority of surrogates also described taking family needs into account when making decisions, and many expressed broader tensions between these needs and a loved one’s values. Some worried about being blamed for the patient’s death by family members who might disagree with a decision to withdraw life support. As one husband said, “If I needed to make the most difficult decision – it was time to end care – and felt that I was being judged, that would be very, very hard to accept.” Others struggled to balance what was best for the patient with what was best for the family. One son described the challenge of making decisions for his mother as “Just trying to deal with the pain that everybody’s [feeling] . . . with . . . what she [the patient] would feel if we kept her alive . . . because I know she’s not going to be happy. What my dad feels, if we let her go, ‘cause I know he’s not going to be happy. And my brother’s not going to be happy, and um... just trying . . . to keep a happy medium, but it’s such a hard situation, that there really isn’t one.”

Coping

Surrogates reported several strategies that eased the burden of decision making. We describe five behaviors and illustrate connections between these coping mechanisms and the tensions we have described. Additional representative quotes are included in Textbox 2.

Textbox 2. Coping Strategies

Coping Strategy	Representative Quotes
Recalling previous discussions	<p>mostly we know exactly what my husband wished. What he thought about these things since our family and friends have been through this before and he’s been there and, uh... his wishes are crystal clear. Umm... and we know the way he lived his life and the way he wanted to live out the rest of his life and, um... uh... we don’t have any problems with making what we feel would be the right decision that would abide by his wishes and that... that’s comforting to know that and some- it’s something that we just didn’t shy away from, but that we discussed in depth in... in our family group. So... so that, that helps a great deal.</p> <p>Fortunately, um... my husband and I had talked about what our wishes were beforehand and we do have an advanced directive and medical power of attorney so we know... um... that we would not want extra special, uh, heroic measures... um.</p>
Sharing decisions with family members	<p>We’re very confident. Up to... including to the point when we actually did move his breathing tube to his trach, um, we actually had to vote. We actually had an actual... we even set up a formal process by which, um, we had to have our decision by Friday at five. . . .And so, we had to actually make it as a vote so that there was no one person that he would get mad at during the times when it got tough.</p> <p>And so, um... it’s been really helpful to have our, our children here with me to make this family decision, um, if... that we may have to make if he doesn’t... um... recover.</p>

Delaying or deferring decision making	<p>I mean if... even if they would have told me at the beginning that they thought there was major brain damage... and... at that point in time, I probably still would've waited a couple days. If they would've asked... you know... at that time, and said that they felt he should have had that - you know, to turn off the life support. I probably still would have waited a couple of days, at least, to make that decision.</p> <p>well, not necessarily the doctors... the social directors and stuff say, "You know... well you gotta... um... always be aware... you gotta make that decision... uh... if something happens." I said, "I'll worry about it when the time comes." She said, "Well you don't wanna wait too long." I said, "Don't rush me. I'll worry about that when the time comes. I'm in no hurry."</p> <p>It's just... uh... you know, the... the fact of the matter is we really don't have a whole lot of say in what's going on. We... we do and we don't. We... we... we have the opportunity to say no, but uh... we know damn well that the doctors are doing everything that they can so it would be foolish on our part to... to take away from her care in any way like that.</p>
Spiritual/Religious Practices	<p>And ...um... I'm not like an avid church person . . . but I do believe in God, and I do pray, a lot. And, this is one instance where all of us were praying, . . . and it's helped . . . I think it gives people something to believe in . . . they're going through a hard period of time, and that's like the only thing that they have left sometimes. So, that's the only... you know... string to grasp onto.</p> <p>I'm just praying to the Lord, that the Lord makes the big decisions, you know? He made this decision that he was going to make it this far, so... 'cause there... last week, downstairs, I didn't even think he was going to make it. And so... that's how I'm taking care of that, the good Lord will make the big decision. And that's it, that's all I can see.</p>
Story-telling	<p>Just sometimes talking about the things that we're going through would help...um... you know, make things clearer, make decisions easier... you know. And, you know, get us... get family members through this time.</p> <p>But, you know, you get to talking together in there [the waiting room] and stuff and it helps. I mean, it makes a difference to... to just have one... to have somebody there that... you know, they're kinda just a sounding board between each other and that. You know, even though you don't know them, sometimes it helps.</p>

Recalling Previous Discussions. The majority of surrogates recalled conversations they had before the patient became critically ill, to focus on their loved one's values and ease the stress of making life or death decisions. As one wife said, *"You know, we're trying everything possible but we're not going to pull out all the stops if it looks like he's definitely not gonna survive . . . we're making the decision to allow him to die . . . so knowing that I'd had that conversation with him, that helps a lot."* Other participants took comfort in recalling previous discussions, but still struggled to interpret their loved one's wishes in the current context. As one husband said, *"She and I had talked many times about what we wanted. And going forward about, you know, quality of life to a point. But we never described what that quality of life is, and everything that we sort of thought was black and white, you know, machines etc, it's very grey."*

Sharing Decisions with Family Members. Almost all surrogates looked to other family members to share the burden of decision making, though a minority found that

family participation made decision making more difficult. Participants involved others to confirm that they were making the right decision and to ensure that different opinions were considered. Sharing decisions eased surrogates' fears about being later blamed for a patient's death or disability. As one wife said, *"I really want our children to be part of that decision [to withdraw life sustaining treatment] . . . because I was afraid that if I didn't they might feel like I had . . . made a decision to end their father's life . . . and I was afraid that there could be resentment about that in the future."*

Delaying or Deferring Decision Making. Many family members reported that they were putting off big decisions. For some, this delay was a chance to reconcile personal or family needs with their loved one's wishes, or to gather and process the information they needed. As one son who faced a decision about a tracheotomy for his father said: *"We've actually delayed and put off decision making as long as possible, on that hope that one day during the time that we have to make the decision that we can actually find the*

person that will give us the real, actual answer.” For others, putting off goals-of-care decisions was a way to avoid thinking about these difficult choices. One son explained, “You know, we don’t want to hear that we’re gonna have to make any other difficult decision right now.” Another son said, “None of those decisions are going to be easy . . . it’s a part of life that I’d like to shove to the side and maybe do without for a while.”

In some cases, surrogates conceptualized treatment decisions as made for them by the medical situation, and this perception seemed to ease the tensions they felt. A sister described her decision to place a feeding tube and a tracheotomy as “fairly easy . . . because there really wasn’t an alternative . . . you know, this was the road that we had to take to improve . . . it was just a given.” Another daughter whose mother was too ill for a high-risk procedure said, “There really was no option . . . and in a sense I’m happy about that . . . I didn’t have to make any huge decisions. Her health made it for me.”

Spiritual/Religious Practices. The majority of family members spoke about prayer as a source of hope, solace and community when facing difficult decisions. A minority described asking God to make decisions for them. One wife described the role she was asked to play as “Real scary. ‘cause I don’t want to be the one saying, you know, ‘we should just let him die’, or just, ‘so he doesn’t have to suffer any longer’ . . . like I said, I want the Lord to take care of that one, you know?” For these participants, involving God in decision making relieved the weight of responsibility they bore and helped them to feel less alone.

Story-telling. Sharing stories also eased the burden and isolation felt by most participants, helping to normalize the intrapersonal tension they experienced. Several family members described the ICU family waiting room as a place where they were able to talk about their hopes and fears with others who faced similar decisions. One wife commented, “You think your situation is bad, but there’s always somebody worse. And my heart goes out to ‘em. But it does you good to talk to people like that. So, that’s one way I cope.” In addition, several participants commented that the study interview itself was therapeutic, thanking our interviewer for “lifting little burdens” by taking the time to listen.

Recommendations for Clinicians

While not a focus of our main analysis, several surrogates made specific recommendations to clinicians about ways to overcome the intrapersonal tensions described. These included facilitating discussions between family members who may hold different views, not pressuring surrogates to make decisions too quickly, allowing families to reconvene

with clinicians soon after hearing bad news to ask questions they may not have thought of at the time, tailoring communication style to family needs (some participants requested more compassionate communication, others requested more statistics and medical facts), and providing a liaison, sounding board, or counselor to listen to surrogates’ stories and coordinate communication with physicians.

DISCUSSION

Using in-depth interviews with surrogates actively involved in decision making for a critically ill patient, we found frequent tension between the desire to respect the patient’s values and fear of responsibility for a loved one’s death, a desire to pursue any chance of recovery, and a need to ensure family well-being. Surrogates utilized a variety of strategies to help manage these intrapersonal sources of stress, ranging from recalling previous discussions and sharing their experiences, to delaying or deferring difficult choices.

Previous research has examined the process of surrogate decision making and factors that affect surrogate distress.^{9,13,14,26} Our study extends this work by focusing on key intrapersonal tensions experienced by surrogates actively facing decisions for a loved one. Such tensions illustrate a potential mechanism for the development of widely-observed psychological morbidity among surrogates months after participating in end-of-life decision making.^{7,15,27}

In addition, our findings provide detailed accounts of why surrogates sometimes struggle to follow the strict substituted judgment standard.^{4,28} Surrogates clearly conceptualized their role as enacting their loved ones’ wishes, yet found adherence to this approach difficult in light of their own or the family’s emotional needs. The internal struggles surrogates described in trying to make decisions according to what their loved one would want at a minimum raise practical questions about how to help surrogates follow a strict substituted judgment standard, as simply urging families to focus on “what the patient would want” may be insufficient when patient preferences conflict with family emotional needs.^{5,6,29,30} These data do not allow us to comment on the ethics of substituted judgment. Some scholars have argued that surrogate decision making be reconceptualized as a process in which family interests are given more ethical consideration.⁵

Surrogates’ coping strategies and recommendations for clinicians suggest several ways that ICU staff could do more to support families. First, by eliciting communication preferences and explicitly acknowledging and attending to surrogate emotions, clinicians may uncover key barriers to decision making and alleviate family distress. Second, by

normalizing the desire to pursue any chance of recovery and inquiring about how this desire may or may not reflect the patient's values, clinicians may help to reframe decisions as a chance to respect a patient's wishes while alleviating the weight of responsibility for decisions and helping surrogates to feel less alone. Third, by encouraging and facilitating family decision making, even when a single durable power of attorney (DPOA) has been designated, clinicians may relieve burdens from individual surrogates and promote family well-being. Fourth, by asking about the importance of religion or spirituality, clinicians may be able to help meet families' spiritual needs and understand how surrogates view God's role in decisions. Finally, when recognizing potentially problematic coping strategies, such as putting off big decisions, physicians may promote more active engagement by clearly describing treatment options, clarifying the surrogate's preferred role, allowing surrogates time to tell their story, and proposing limited trials of intensive treatment with defined times for reevaluation.³¹

Our findings should be interpreted in light of several limitations. This study was conducted in ICUs at two hospitals in Pittsburgh; the experience of surrogates may differ at other sites or in non-ICU settings. In addition, it is possible that surrogates who did not participate may differ in significant ways from those who did. However, most surrogates who declined to participate were feeling too overwhelmed to consider taking part in research, thus it seems likely that the tensions we highlight would also be present in this group. Finally, because our sample was predominantly Caucasian, we were unable to explore potential differences in the surrogate experience by race or ethnicity.

Increasing attention to the negative experience of surrogates has led to widespread calls to improve support for families in the ICU. Our study findings lend depth to our understanding of the sources of intrapersonal tension for surrogates faced with life or death decisions for someone else and illustrate several coping behaviors that may inform strategies to alleviate psychological burdens and improve the quality of care for critically ill patients and their families.

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