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## Acutely-bereaved Surrogates' Stories about the Decision to Limit Life Support in the ICU

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### Abstract

**Objective**—Participating in a decision to limit life support for a loved one in the intensive care unit (ICU) is associated with adverse mental health consequences for surrogate decision makers. We sought to describe acutely-bereaved surrogates' experiences surrounding this decision.

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**Design and setting**—Secondary analysis of interviews with surrogates approximately 4 weeks after a patient's death in one of 6 ICUs at 4 hospitals in Pittsburgh, Pennsylvania.

**Subjects**—Adults who participated in decisions about life support in the ICU.

**Interventions**—n/a

**Measurements**—We collected participant demographics, prior advance care planning, and decision control preferences. We used qualitative content analysis of transcribed interviews to identify themes in surrogates' experiences.

**Main results**—The 23 participants included the spouse (n=7), child/step-child (7), sibling (5), parent (3), or other relation (1) of the deceased patient. Their mean age was 55, 61% were women, all were white, 74% had prior treatment preferences discussions with the patient and 43% of patients had written advance directives. 15/23 (65%) surrogates preferred an active decision-making role, 8/23 (35%) preferred to share responsibility with the physician and no surrogates preferred a passive role. Surrogates report that key stressors in the ICU are the uncertainty and witnessed or empathic suffering. These factors contributed to surrogates' sense of helplessness in the ICU. Involvement in the decision to limit life support allowed surrogates to regain a sense of agency by making a decision consistent with the patient's wishes and values, counteracting surrogates' helplessness and ending the uncertainty and suffering.

**Conclusions**—In this all-white sample of surrogates with non-passive decision control preferences from a single US region, participating in decision making allowed surrogates to regain control, counteract feelings of helplessness, and end their empathic suffering. While prior research highlighted the distress caused by participation in a decision to limit life support, the act of decision making may, counter intuitively, help some surrogates cope with the experience.

## Keywords

surrogate decision maker; ICU; bereavement

## Introduction

One in five people in the US die in an intensive care unit (ICU) or shortly after ICU discharge [1]. Many ICU deaths are preceded by decisions to discontinue life-sustaining treatments. Clinicians often ask family members to participate in these decisions as surrogate decision makers, guided by their understanding of the patient's wishes and values [2]. However, participation in such decisions can place an emotional burden on surrogates [3, 4] and has been associated with adverse mental health effects, including post-traumatic stress disorder (PTSD), anxiety, depression, and complicated (prolonged) grief [5-7].

A prevailing assumption is that the decision making process itself is distressing to surrogates [8]. Studies document surrogates' expressions of regret [9], self-blame [10, 11], and doubt, with many surrogates asking themselves “Did I do the right thing?” after making a decision to withdraw life support [12], particularly when the patient's wishes were not known [13]. One of the characteristics of this body of research is that interviews are usually conducted 3 to 6 months after the ICU decision-making experience.

The purpose of the current study is to describe bereaved surrogates' ICU experiences within the first few weeks after their participation in a decision to limit life support. By eliciting surrogates' stories earlier in the bereavement period, we expect improved recall and a less organized, or constructed, narrative. These early narratives may provide a unique perspective upon which to develop hypotheses regarding the elements of the ICU and decision making experience that may affect mental health outcomes.

## Materials and Methods

### Study Design, Participants and Setting

This is a qualitative analysis of in-depth, single-session semi-structured interviews with surrogate decision makers (surrogates) conducted approximately 4 weeks after the death of their loved one following a decision to limit life support in the ICU. We conducted interviews as part of the parent pilot clinical trial to test the feasibility, acceptability, and tolerability of storytelling to reduce emotional distress among surrogates. We describe our conceptual framework and developmental work on the storytelling guide elsewhere [14]. This is the first analysis of the content of these interviews.

We recruited surrogates from 6 ICUs (3 medical, 2 surgical and 1 mixed medical-surgical) at 4 hospitals (2 academic tertiary care centers and 2 academically-affiliated community hospitals) in Pittsburgh, Pennsylvania. Eligible participants included adults who self-identified as the primary medical decision maker for an incapacitated patient on life support (mechanical ventilation, vasopressors, dialysis or feeding tube) in the ICU. To recruit surrogates, we used a two-step consent process. We obtained initial consent at the patient's bedside for permission to assess eligibility through review of the patient's medical record and to re-contact the surrogate after the hospitalization. If the patient then died after a decision to limit life support, they became eligible for the second step. We mailed the surrogate a condolence letter and further information about the study, then called to obtain consent for continued participation. Participation involved assignment to a storytelling interview for 6 subjects in the developmental phase of the pilot trial and for 18 subjects in the feasibility, acceptability, and tolerability phase (See supplementary material).

### Data Collection

A trained health care professional (physician or social worker) conducted a 40-90 minute semi-structured storytelling interview with each surrogate. Interviewer training included skills practice and iterative team feedback on completed interviews, resulting in moderately high inter-interviewer adherence to the interview protocol. Interviews took place in the participant's home, a private conference room or, for participants who lived more than 50 miles from Pittsburgh, by telephone. As described elsewhere [14], the goal of the interview protocol was to elicit the surrogate's story of the ICU experience and its aftermath, with a focus on empathic listening. Interviewers were trained to probe emotional, not historical, content for elaboration, because our goal was to draw out the surrogate's experience. We included the interview guide as an appendix.

We collected basic demographic information for both the patient and the surrogate when the surrogate first consented to be re-contacted in the ICU. We reviewed the medical record of deceased patients and recorded the reason for ICU admission, Acute Physiology and Chronic Health Evaluation (APACHE) III score [15], and any documentation regarding surrogate participation in decision making.

Also as part of the pilot trial, the study team collected additional information from surrogates prior to the storytelling session by telephone using validated questionnaires [14]. Items included whether the patient had a living will, whether surrogate had previously discussed treatment preferences with the patient, and the Degner Control Preferences Scale [16], which has been previously used in ICU surrogate decision makers [17, 18]. The Control Preferences Scale is composed of five potential roles in clinical decision making available as choices on a 1 through 5 scale with increasing scores indicating a preference for increased physician control in decision making.

### Qualitative Data Coding

We audio recorded and transcribed the interviews verbatim. To develop the preliminary coding framework, members of our multidisciplinary team independently listened to an audio file and read the associated interview transcript. Our team included investigators from diverse backgrounds including palliative care (YS, RMA), critical care medicine (AEB), medical school (ERN), psychiatry (CFR) and psychology (MAD). We met in person and used inductive content analysis to develop preliminary codes, without pre-formulated hypotheses or theories [19]. During our meetings we also used the technique of constant comparison, through which codes were continuously refined against previous applications of the code [20]. We stopped conducting analysis meetings after reviewing six (26%) interviews together when we began approaching thematic saturation, at which point codes and themes were found to have a predictable regularity within the interviews [21]. This constant comparative process with investigators from a variety of professions allowed for broader and more generalizable themes to emerge and led to the formation of a preliminary codebook that could then be applied to all interviews.

To refine this codebook, two coders (EN & IJ) applied the preliminary framework to a total of 4 interviews (17%). They met and discussed their codes to assess any discrepancies and resolved disagreements through a consensus process, adjudicated by the principal investigator (AB). Preliminary coding led to the iterative development of a more robust codebook through refinement of existing codes and the addition of new codes.

After developing a robust framework, one investigator applied the codebook to all the interviews using Atlas.ti (Berlin, Germany). Four investigators analyzed these codes inductively to generate higher level themes, which we then discussed as a larger team. This process of qualitative interpretation [22-24] supported the development of common themes in the experiences of surrogates that may be playing a role in adverse emotional health outcomes

## Statistical analyses

In addition to summarizing key themes emerging from the interviews, we summarize participant characteristics and survey item responses using measures of central tendency including means, medians, and proportions, as appropriate.

## Human subjects

The University of Pittsburgh institutional review board reviewed and approved this study. All participants provided written informed consent.

## Results

### Participant characteristics

**Demographics:** Overall, 40/63 (63%) of eligible subjects agreed to participate. Following the study design of the parent study, we assigned 24/40 (60%) to storytelling, of whom 23 (96%) completed the interview. Participants included the spouse, sibling, parent or child of the deceased patient. In 5 (22%) of cases, progress notes named the subject as primary decision maker, in 4 (17%) of cases notes named the subject as one of two or more decision makers, in 11 (48%) of cases the notes named “the family” as decision maker or used the passive voice to reference the family (e.g., “After a family meeting *it was decided...*”) and in 3 (13%) of cases notes did not reference a decision making process. We summarize subject characteristics in Table 1. Surrogates' mean age was 55, 61% were women, and all were white. Patients' most common reasons for ICU admission included acute respiratory failure (10/23) and shock (9/22), their mean admission APACHE III score was 79 and length of stay was 13 days.

**Patient preferences and advance directives:** 17/23 (74%) surrogates reported having had a discussion with the patient before admission to the ICU about what treatments the patient would want if they were too sick to speak for themselves and 10/23 (43%) reported that the patient had a written living will or advance directive.

**Decision Making Preference:** 15/23 (65%) surrogates reported that they preferred to have final control in decision making over life sustaining treatments. Another 8/23 (35%) reported that they preferred to share responsibility for the decision with the doctor, while no surrogates reported that they wanted the doctor to have final control in decision making.

### Qualitative Results

Surrogates related their distress in the ICU environment to uncertainty about prognosis and witnessing the bodily suffering of their loved ones. These factors contributed to surrogates' sense of helplessness in the ICU. For most, involvement in the decision to limit life support allowed surrogates to regain a sense of agency. In several instances, surrogates described that making the decision brought a sense personal relief. We explore these themes in detail below.

## Stressors in the ICU

**Prognostic Uncertainty:** One of the most distressing aspects for surrogates was the daily uncertainty of not knowing when or if the patient was going to get better. A constant sense of anxiety and dread took a mental toll on all surrogates. As one surrogate (1-005) described it: “I don't know if you're just numb, because it's so exhausting, and it was a month of exhausting because I was stressed about work, and I was at the hospital, and what's going to happen? You are waiting for the phone to ring, there's always a panic. The fear of the phone ringing in the middle of the night kind of a thing.” Another surrogate (2-064) explained “It's nerve-racking every day, not knowing what to expect.” Some surrogates reported managing this uncertainty by being hopeful, staying positive, or through prayer. As one participant (2-169) said, “I think you're praying for that miracle the whole time. You just pray. The night was the worst for me. I would get home and break down. And just pray to God that tonight something miraculous would happen.”

**Witnessed Suffering/Suffering Witness:** Another of the most difficult aspects for surrogates was witnessing bodily suffering. All surrogates reported that they perceived that the patient was suffering and/or reported their own empathic suffering witnessing the patient's bodily state. While most surrogates did not differentiate between the patient's suffering and their own empathic suffering, several did, including this surrogate (2-064):

Well, seeing how she was on the ventilator and hooked up to a dialysis machine. It hurt just to see. A lot of poking and prodding. Her arms were a thing of blood and she just was a mess. It was hard to see that. Especially, two weeks. Two solid weeks of that. It was hard for everybody just to see her in that condition. Because everyone was so used to seeing her happy.

For many, the distress over witnessing the bodily changes was more existential, involving what they perceived as a loss of the patient's personhood, rather than physical suffering. One surrogate (2-122) explained: “She wasn't my mom. She wasn't there. Her body looked different. It was almost like she was there with me mourning over this thing that everyone said was [her]. But it wasn't her.” Another surrogate (1-005) described how she tried to give an identity to her brother for the medical team “It was very stressful because he had no life about him. There were so many machines and tubes. I kept telling the nurses what he was like, because I know that they just see a body that they're treating.”

**Feelings of helplessness:** Prognostic uncertainty and witnessing the bodily state of the patient led to surrogates feeling a sense of helpless passivity in the ICU. The wife of a patient in the ICU (1-009) described the ICU experience as “Brutal Hell. This whole process has just ripped the life out of me. My husband suffered greatly for all of this. This is just something that you don't ever wanna see a loved one go through. At all.Ever. And to watch somebody that you love hurt and not be able to help them, sucks.” The son of a father who had a bad fall said (2-169)“I kept waiting for his breathing to improve. Looking at the monitors and the breathing apparatus and just waiting to see his vitals improve, staring at them nonstop, just waiting for the water to boil. And it was exhausting. It really was.”

## Decision Making

**Importance of Prognosis and Patient Values:** Most surrogates described a turning point leading to the decision to withdraw life support, often associated with a discussion with the clinical team about prognosis in relation to the patient's values. One surrogate explained (1-005): “I think at that point is when we talked about what would he want and would he want to live. Part of it was would he want to – if he had survived, would he want to live? Could he have even lived through the rehabilitation?” Another surrogate (2-064) describes how he arrived at his decision to limit life support for his wife:

The infection pretty much had taken over her whole body. And the doctors got us together. Her legs were basically purple. It was getting to a point where she couldn't fight anymore. And they even mentioned, if [she] somehow miraculously gets through the infection, there was no guarantee her mental capacity was even gonna be there. So that was another factor that, I just thought she would never have wanted to be like that at all.

The immediate and longer-term functional prognosis of the patient provided by the medical team was a key driving force behind families thinking about the patient's values and making the decision.

**Taking Control:** Many surrogates reported that decision making allowed them to reassert their sense of agency after a period of uncertainty, witnessed suffering, and helplessness. One surrogate (2-064), the husband of a patient with cancer, recounted taking control of the situation:

They were giving her like three, four antibiotics, the strongest they could give her to try and fight the sepsis, but [it] just basically had taken over her body. And her legs were starting to blister and at that point, I was just like ‘that's enough. She's had enough.’ I was the one that said, [what] we have to do. ‘We can't go through this anymore.’

Asserting control allowed him to protect his wife (“she's had enough”), himself and his children (“we can't go through this anymore”). Another surrogate explained the positive experience of asserting her agency by making a decision (2-122):

But in that moment on the 30th when I woke up I knew that day that it was over. My mom didn't have to just lay there anymore. We didn't have to struggle with what's going on with her. It just was a relief to finally have an answer to what was gonna happen. And for me, I'm a control freak. So I had control over that situation. I was making the decision. I no longer had to watch my mom struggle and me be helpless about it. And so to me – I was peaceful that day.

**Relief:** Many surrogates described a similar feeling of relief after having made the decision. The decision gave them chance to honor the patient's wishes and/or they were relieved to know their loved one was no longer suffering. Moreover, their own suffering, caused by continued uncertainty and witnessed bodily suffering, ended. The sister of a patient suffering from multi-organ failure said about the day of limiting life support (2-169):

That day I was at peace. It just is something comes over you that you feel like you're doing the right thing, that this is better. It was almost a guilty feeling of peace. I felt good that he was out of his misery. I felt good that he wasn't suffering. It's weird. It was almost joyous. I was sad, but it was okay.

Many surrogates used the term “the right decision,” based on their understanding of the patient as a person. For example, the husband of a patient with lung disease said (1-049) “I don't want to call it an easy decision. It's not an easy decision, but if you know the background of what her thoughts were and what she went through, how she dealt with her father's and her mother's death, you had to know it was the right decision. And knowing it's the right decision, gives you a calmness in a sense.” For many other surrogates, the experience was also spiritual. For the daughter of a patient who had a cardiac arrest (2-153) “I felt good about that part of it and deciding to take my mother off the oxygen was an easy decision actually, because I would not put my mother through more. I wanted her to go into the arms of the Lord.”

**Questioning the Decision:** Only 3 surrogates reflected on the possibility that they may have limited life support too early and not given the patient a full opportunity to recover. The sister of a patient with multisystem organ failure explained (1-005): “And you do question. I would read the websites about people that survived and should we have waited? What if? But in reality, it's a miracle you're waiting on.” Another surrogate had difficulty making the decision to limit life support and she recalls (2-174):

I do feel I fought [for the patient] as hard as I could. I still regret that I think I should have fought more, but it would have been for me, not him. And that's the decision. You have to think of that person, not yourself. Was it fair for me to keep him alive so I could go down there and hold his hand? No. It felt right for me, but it wasn't right for him.

The same participant also had difficulties making the decision to limit life supported because it made her feel responsible for the death of her husband. When asked about how she felt about signing the Do Not Resuscitate (DNR) document, the surrogate stated (2-174): “I couldn't sign it for a long time. I wanted to, but I couldn't. It's like signing his death warrant. But I knew it had to be done. I wish I wouldn't have had to sign it.” This participant was unique in our interviews because she was the only one to express regret about participating in the decision.

## Discussion

In this qualitative study of 23 surrogates involved in decision making about life support for an incapacitated loved one who died in the ICU, uncertainty, witnessed (empathic) bodily suffering, and helplessness in the face of these experiences were key stressful stimuli. For most, involvement in the decision to limit life support provided surrogates with a sense of agency by making a decision that was consistent with their loved one's values and offering relief by delivering surrogates from uncertainty and continued suffering.



Previous literature has suggested that involvement in the decision to limit life support may be harmful to families and may be the cause of the adverse mental health outcomes associated with being a surrogate decision maker [13, 25]. Our work suggests that although the decision to limit life support is very difficult, the making of the decision, in and of itself, may not be the key stressor causing harm for most surrogates. Nonetheless, we did identify some exceptions. One surrogate in particular, strongly regretted being asked to sign the DNR papers for her husband. She attributed direct harm to that concrete involvement. We felt that her case was unique in our study population because having to sign a document may accentuate the burden of responsibility and is not commonly done in clinical practice [26]. The handful of other surrogates who expressed some ambivalence about the timing of their decision to limit life support did not express any regret about being *involved* in decision-making. Therefore, we posit that involvement in decision-making may be helpful for many surrogates because it gives them opportunity to have some control over the situation, but that a subgroup of these surrogates may nevertheless experience some ambivalence over the choice they made.

One of the mechanisms behind the potential benefit of being actively involved in decision-making may be that it allows families to make decisions consistent with the patient's wishes. This may explain why when patients have advance directives or patient preferences are previously known, surrogates report higher rates of satisfaction with the decision to limit life support [3, 27, 28]. Of note, our sample population had rates of advance directives and prior treatment preferences representative of the general American population [29, 30]. For most participants in our study, being actively involved in the decision-making process allowed surrogates to regain control and emerge from the distress caused by continued uncertainty and witnessed suffering. This may explain why, in other studies, surrogate decision makers with an active decision making style have lower rates of depression and anxiety compared to those who prefer a more passive role in decision making [5]. Others have shown that surrogates have higher rates of depression and PTSD when there is a discordance between their decision making preference and their actual decision making role [31].

A strength of this study was that the interviews were part of a pilot trial to test the feasibility of storytelling as an intervention to reduce adverse mental health outcomes among surrogate decision makers. As a result, the interviewers followed a consistent guide designed to elicit the surrogates' experience using empathic listening, and explicitly avoided any guidance to change behavior, thoughts, or feelings. We do not believe that the storytelling intervention affected the surrogates' recollection and retelling of the narrative. While each of our subjects self-identified as surrogate decision makers, a limitation of this study is that retrospective medical record review of progress notes could not definitively confirm the subject's actual role in decision making. Specifically, the majority of notes references multiple decision makers without specifying the individual acting as "legally authorized representative" and usually failed to document decision makers by name or relationship, more commonly referring to them as "the family." Another limitation of this study is that our sample included only surrogates whose loved ones died. This was by design for the pilot clinical trial that focused on bereaved surrogates at highest risk for adverse emotional health outcomes. Surrogate decision makers of patients who survive to discharge are also

predisposed to emotional distress from the ICU experience and subsequent caregiving [32]. It may be that these two sets of surrogate decision makers share common experiences that put them at risk. On the other hand, they may be distinct in important ways. Our study does not allow us to comment on the experiences of surrogates whose loved ones survived. Another limitation is that we were only able to interview participants who agreed to participate in the storytelling interview after their loved one died. It is possible that there might be a systematic difference between the participants who agreed and those who declined continued participation in the study. For example, participants who agreed may be more likely to have active decision control preferences. Additionally, those surrogates experiencing the greatest distress may have been less likely to participate. Indeed, one common reason that surrogates gave for declining participation is that they were currently overwhelmed. Another major limitation is that the sample is from one US region and is racially homogenous. The racial homogeneity may reflect reservations about participation in research on this topic among African-Americans in our region. Reasons given by African Americans for declining to enroll in the trial included that the incapacitated patient had previously declined research participation and that they had other sources of help (e.g., their faith).

Families of patients in the ICU who are asked to serve as surrogate decision makers are at increased risk of adverse emotional health outcomes. Our study adds to the literature by highlighting the sense of uncertainty, witnessed suffering, and helplessness pervasive in the ICU environment that may predispose to these outcomes. Some possible approaches to counteracting this distress might include: improved communication with family and engaging them, not only in decision making, but also in daily patient caregiving [33] and staff recognition of patients' personhood through inquiries regarding the patient as a person [34, 35]. It is possible that engaging families to the degree that they want to be involved may increase their sense of agency, counteract the sense of helplessness in the ICU, and reduce the distress from being an ICU surrogate.

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**Table 1**  
**Participant Characteristics**

<b>Variable</b>	<b>Patients (n=23)</b>	<b>Surrogates (n=23)</b>
Female, n (%)	11 (48)	14 (61)
Age (years), mean (SD)	63 (15)	55 (12)
Race/ethnicity, n (%)		
Non-Hispanic White	23 (100)	23 (100)
Religious Preference, n (%)		
Protestant Christian	6 (26)	9 (39)
Roman Catholic	9 (39)	7 (30)
Other Christian	7 (30)	5 (22)
Jewish	0 (0)	0 (0)
Agnostic/Atheist/No religion	2 (9)	(0)
Other	3 (13)	3 (13)
Relationship to patient, n (%)		
Spouse/partner		7 (30)
Child/Step-child		7 (30)
Sibling		5 (22)
Parent		3 (13)
Other		1 (4)
Subject named in EMR progress notes as decision maker		
Named* as primary decision maker		5 (22)
Named* as one of 2 or more decision makers		4 (17)
No one specific named; notes reference "the family"		11 (48)
No documentation of decision making process		3 (13)
Importance of Religion or Spiritual Beliefs		
Not at all important		1 (4)
Not too important		2 (9)
Fairly Important		6 (26)
Very Important		14 (61)
Highest Level of Education		
Graduate of Professional Degree		5 (22)
Completed college		8 (35)
Some college		9 (39)
High School diploma or GED		1 (4)
Total Household Income		
Less than \$20,000		2 (9)
\$20,000-\$39,999		4 (17)

Variable	Patients (n=23)	Surrogates (n=23)
\$40,000-\$59,999		4 (17)
\$60,000-\$79,999		4 (17)
\$80,000-\$99,999		2 (9)
More than \$100,000		3 (13)
Decline to answer		5 (22)
<hr/>		
ICU Admission		
APACHE III Score, mean (SD)	79 (32)	
Length of Stay (days), mean (SD)	13 (9.7)	

EMR – electronic medical record

APACHE III – Acute Physiology and Chronic Health Evaluation – 3<sup>rd</sup> Edition

\* named by name or by relationship (e.g. “mother”)

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