Intensivist-reported Facilitators and Barriers to Discussing Post-Discharge Outcomes with Intensive Care Unit Surrogates

A Qualitative Study

Alison E. Turnbull^{1,2,3}, Wesley E. Davis^{1,2}, Dale M. Needham^{1,2,4}, Douglas B. White^{5,6,7}, and Michelle N. Eakin^{1,2}

¹Outcomes after Critical Illness and Surgery Group, ²Division of Pulmonary and Critical Care Medicine, School of Medicine, ³Department of Epidemiology, Bloomberg School of Public Health, and ⁴Department of Physical Medicine and Rehabilitation, School of Medicine, Johns Hopkins University, Baltimore, Maryland; ⁵Center for Bioethics and Health Law, Department of Critical Care Medicine, ⁶Clinical Research, Investigation, and Systems Modeling of Acute Illness (CRISMA) Center, Department of Critical Care Medicine, and ⁷Program on Ethics and Decision Making in Critical Illness, Department of Critical Care Medicine, University of Pittsburgh, Pittsburgh, Pennsylvania

ORCID ID: 0000-0002-1564-6547 (A.E.T.).

Abstract

Rationale: Intensive care unit (ICU) patients' expected post-discharge outcomes are rarely discussed in family meetings despite this information being centrally important to patients and their families.

Objectives: To characterize intensivist-identified barriers and facilitators to discussing post-discharge outcomes with surrogates of ICU patients.

Methods: Qualitative study conducted via one-on-one, semistructured telephone interviews with 23 intensivists from 20 hospitals with accreditation council for graduate medical education–accredited critical care medicine programs in 16 states. A limited application of grounded theory methods was used to code transcribed interviews and identify themes and illustrative quotes.

Measurements and Main Results: Intensivists reported tension between their professional responsibility to discuss likely functional outcomes versus uncertainty about their ability to predict those outcomes for an individual patient. They cited three main barriers as limiting their ability to conduct conversations about post-discharge

outcomes with ICU surrogates: (1) incorrectly optimistic expectations for recovery among ICU surrogates, (2) having little or no contact with their patients after ICU discharge, and (3) minimal confidence applying existing outcomes research to individual patients. Despite these barriers, experience talking to ICU surrogates, seeing ICU survivors in the outpatient setting, and trusted research on functional outcomes were identified as important facilitators to discussing likely patient outcomes with surrogates. Intensivists generally welcomed questions from surrogates about post-discharge outcomes as opportunities to initiate conversations about prognosis and patient values.

Conclusions: In this sample of intensivists from 20 academic hospitals, experience conducting conversations with surrogates and interactions with ICU survivors as outpatients were identified as facilitating discussion of expected post-discharge outcomes while optimistic surrogate expectations and prognostic uncertainty were barriers. There was tension between self-perceived ability to prognosticate and belief in a professional obligation to discuss patient outcomes.

Keywords: critical care; patient-centered care; prognosis; communication barriers; surrogate decision-making

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Correspondence and requests for reprints should be addressed to Alison E. Turnbull, D.V.M., M.P.H., Ph.D., Pulmonary and Critical Care Medicine, Johns Hopkins University, 1830 E. Monument Street, 5th Floor, Baltimore, MD 21205. E-mail: turnbull@jhmi.edu

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The number of patients requiring mechanical ventilation in an intensive care unit (ICU) continues to increase as the population ages (1–3). Simultaneously, in-hospital mortality rates for many diseases including acute respiratory failure, severe sepsis, pneumonia, and chronic obstructive pulmonary disease (COPD) are declining (4–7). The net result is a rapidly growing population of ICU survivors. For many, surviving critical illness comes at a substantial “cost” related to new or worsening long-term physical (8, 9), cognitive (10–12), and psychological impairments (13, 14). These problems, which often persist for years after acute hospitalization, have been termed post-intensive care syndrome (15).

A policy statement endorsed by two critical care professional societies calls on intensivists to routinely discuss the risk of these new impairments with ICU patients and their families (16). The vast majority of ICU patients cannot participate in decisions about their care (17). As a result, ICU surrogates (generally family members of the patient) are challenged with speaking on the patient’s behalf. Physicians almost universally provide surrogates with medical information about the patient’s condition and at least one treatment option (18, 19). However, ICU physicians are generally reluctant to discuss a patient’s expected quality of life, functional prognosis, or survival (20–22), and discussed patients’ expected physical and cognitive function in only 12% of recorded family meetings (23). This is concerning, given that post-discharge outcomes are centrally important to patients and their families when making treatment decisions (24).

In this study, we sought to characterize intensivist-identified barriers and facilitators to discussing post-discharge outcomes with patient surrogates. We elicited input from a diverse group of experienced intensivists as a first step toward identifying acceptable ways to incorporate information about post-discharge outcomes into the shared decision-making process in the ICU setting.

Methods

Participants

We recruited intensivists at hospitals with accreditation council for graduate medical education–accredited critical care medicine

programs, who participated in a previous study evaluating communication with surrogates of ICU patients (25). In the prior study, participants reported their willingness to bring up the option of withdrawing life support in 10 hypothetical patient scenarios (25). From this trial, a score ranging from 0 to 40 was computed for each participant, with higher scores indicating greater likelihood that they would raise the option with patient surrogates under more scenarios (25).

To obtain a diversity of perspectives, we used maximum variation sampling (26) to ensure diversity of sex, years of clinical experience, base specialty, and scores from the 2014 study. Selected intensivists received an e-mail invitation to participate in a 30-minute, one-on-one, telephone interview and respondents were asked a single screening question: “Have you spent at least 4 weeks performing clinical work in an ICU during the last 12 months?” All intensivists who responded to the e-mail invitation were scheduled for an interview. Oral informed consent was provided before the interview and intensivists were offered \$175 as compensation for participation. The Johns Hopkins University Institutional Review Board approved this study.

Interviews

Semistructured, telephone interviews were conducted during May 2015, using a written interview guide (see Appendix 1 in the online supplement). The interview guide was constructed and iteratively revised on the basis of six pilot interviews with intensivists before study recruitment. The interview guide asked intensivists open-ended questions about scenarios in which discussions about post-discharge outcomes might be discussed in the ICU, followed by prompts to understand why discussions do or do not occur and how intensivists conduct them. All telephone interviews were conducted by a single trained researcher, audiotaped, and then transcribed by a professional medical transcriptionist.

Analysis

Transcripts of the interviews were analyzed with NVivo 10.0 software (2013; QSR International Pty Ltd, Doncaster, Australia). Two coinvestigators who did not conduct the interviews (A.E.T., W.E.D.) read all transcripts and inductively developed a written codebook containing theme names

and definitions, using thematic analyses (27). Thereafter, the same coinvestigators independently coded each transcript, with a third investigator (M.N.E.) consulted for discrepancies. Frequencies of themes across participants were tabulated, and coding was compared on the basis of percentage agreement and Cohen’s κ coefficient. Coding between the two raters demonstrated good agreement (percent agreement, 99%) and moderate interrater reliability (Cohen’s κ = 0.71).

Results

A total of 23 participants from 20 hospitals in 16 states responded to the invitation e-mail, passed the eligibility screening, and were able to schedule and complete an interview within 7 weeks of the invitation. Participants had a range of base specialties, with the most common being internal medicine (Table 1). The median number of years since completing medical school was 22 (range, 6–46). The median score among interviewed participants was 25 (range, 0–40). The mean interview duration was 24 minutes (SD, 6 min). Overall, intensivists reported feeling a tension between their professional responsibility to discuss likely

Table 1. Demographics of interviewed intensivists

Characteristic	Value
Male, n (%)	20 (87%)
Specialty, n (%)	
Medicine	19 (83%)
Surgical	3 (13%)
Anesthesiology	2 (9%)
Years since medical school graduation, median (range)	22 (6–46)
Willingness to discuss withdrawing life support score,* median (range)	25 (0–40)
Current practice region, n (%) [†]	
Northeast	11 (48%)
South	7 (30%)
Midwest	4 (17%)
West	1 (4%)

Number of interviewed intensivists: n = 23.

*Score derived from participation in previous trial on reported willingness to bring up the option of withdrawing life support (25). Possible scores range from 0 to 40, with higher scores indicating the participant reported he or she would bring up the option under a greater number of hypothetical scenarios.

[†]Region is defined by U.S. census region.

functional outcomes and being uncertain about their ability to accurately predict those outcomes. As described subsequently, there were three themes regarding the key barriers and facilitators associated with addressing this dilemma, which were the role of (1) surrogate expectations, (2) clinical experience, and (3) outcomes research (Figure 1).

The Role of Patient Surrogates

Participating intensivists were asked how they feel about responding to questions asked by patient surrogates about post-discharge outcomes. Most intensivists identified professional responsibility as a primary reason to address these questions (Table 2). This responsibility was often described as an obligation to assist ICU surrogates in making informed decisions about treatment by providing functional prognoses. Simultaneously, uncertainty in their ability to accurately prognosticate generated tension with this professional responsibility. As one intensivist (Intensivist 12) said:

I don't know that I can answer that question [about post-discharge outcomes] accurately, but I feel like I owe it to patients' families to try, and that's where it gets tricky—that's where the rub is, right?

In addition to struggling with prognostic uncertainty, many intensivists described unrealistic optimism about recovery among ICU surrogates as a barrier to discussions of post-discharge outcomes (Table 2). For example:

They [surrogates] tend to have an overly optimistic view of what can happen with serious illness. Their expectations are very, very different than what often happens to patients (Intensivist 2).

Some intensivists reported that families rarely ask any questions about functional recovery while others described surrogates as exhibiting a hierarchy of informational needs in which functional outcomes are not considered until patient survival and discharge are assured. As Intensivist 17 described:

At different phases [surrogates] have different needs and typically when they talk with us their needs are still primal and survival based and therefore the meaningful questions that really hit the boiling point don't arrive until the patient is about to be discharged.

The Role of Clinical Experience

Although participants were not asked whether they practiced outside the ICU, many mentioned that their experience in treating patients outside the ICU influenced their discussions with surrogates. Some intensivists cited their clinical contact with ICU survivors as reducing uncertainty about functional outcomes for ICU patients (Table 3). Intensivists frequently mentioned that confidence was gained through contact with survivors in the outpatient setting.

Conversely, intensivists not practicing in the outpatient setting cited lack of contact with survivors as contributing to uncertainty

about post-discharge outcomes. As Intensivist 14 explained:

As critical care physicians we're seeing them for a short window of acute illness and then boom, we're shipping them off to the hospital or we're shipping them off to rehab....I only see them acutely in the ICU and I don't work at long-term rehab, so I don't see the downstream effects.

Intensivists who were comfortable discussing functional outcomes despite prognostic uncertainty often identified experience interacting with patients and families as the foundation of their confidence (Table 3). When asked why he/she was comfortable discussing post-discharge outcomes, Intensivist 11 replied:

Because I've been practicing in the intensive care unit for 25 years. I've talked with a lot of patients.

This sort of experiential learning was usually gained after completion of postgraduate training.

I wasn't trained to think that way [about post-discharge outcomes] during my residency or fellowship training. I've had to learn about this in my own practice (Intensivist 20).

The Role of ICU Outcomes Research

Participating intensivists were not asked about research. However, most intensivists mentioned research. Research was discussed as either a barrier or facilitator to

Figure 1. Factors identified by intensivists as barriers (*left*) and facilitators (*right*) to discussing post-discharge outcomes with the families of intensive care unit (ICU) patients.

Table 2. Role of intensive care unit surrogates in discussions about post-discharge outcomes

	Facilitator	Barrier
The relationship between intensivists and ICU surrogates	<i>I feel it's an integral part of my job....I have a responsibility as a physician to at least make a conjecture to help give them some guidance, particularly when they're trying to make tough decisions.—Intensivist 12</i>	<i>[One problem] is the misperception on the part of a lot of people that somehow medicine has got insights, knowledge, technologies, and powers that only God has....There is an unrealistic expectation on the part of the population.—Intensivist 21</i>
	<i>If we don't have a reasonable expectation of survivorship and return to function, then we have to sit down with a family and be honest with them.—Intensivist 21</i>	<i>Most families don't have a good concept of recovery and what happens post the acute hospitalization.—Intensivist 11</i>
	<i>I think we have a responsibility for answering those questions [about functional outcomes]—Intensivist 5</i>	<i>When we talk about survival to go home they [surrogates] don't understand that we are talking about survival that may be in a physical condition that is very different from what they [the patient] had originally had.—Intensivist 6</i>
	<i>We try to assess the prognosis for the patient and then explain to them what we know and what we don't know....It's just what we [intensivists] do.—Intensivist 16</i>	<i>Families sometimes have very unrealistic expectations of what they can provide in the home, and we've had lots of family members want to take patients home despite their requiring a lot of skilled care and some degree of life-supportive care and then unrealistic expectation that, oh we can get a ventilator in the home, we can do dialysis in the home.—Intensivist 10</i>
	<i>It's an important part of my job to be able to tell them and the families what to expect in the future....I feel it's probably either most important or as important as trying to understand the patient's medical problems and treat them....That's the business we're in.—Intensivist 2</i>	

Definition of abbreviation: ICU = intensive care unit.

discussions of post-discharge outcomes, and sometimes discussed as both by the same intensivist (Table 4). When Intensivist 2 was asked why he/she felt comfortable discussing post-discharge outcomes, he/she replied:

I try to keep up with that part of the [research] literature.

Other intensivists described the quality of existing research as insufficient or immature. For example:

I don't think that the state of the science permits us to adequately predict what the future will hold from a long-term outcomes perspective for patients (Intensivist 17).

Still others described clinical research as inherently incapable of informing discussions about individual patients regardless of quality.

Surrogate Questions as Opportunities

When asked what surrogates of ICU patients should ask during discussions with the ICU care team, many intensivists said they welcome questions related to future ability to participate in activities or relationships valued by the

patient. This finding was conveyed in statements like:

I want the family, knowing what's important to the patient, to ask me if I thought the patient could achieve those goals.

Some intensivists suggested that waiting for surrogates to ask questions about post-discharge outcomes was unduly burdensome. These intensivists reported they would provide prognostic estimates for post-discharge recovery regardless of surrogate questions. As Intensivist 4 said:

The family shouldn't need to ask....those issues should be brought up by the physician.

Multiple intensivists described an ideal situation in which surrogates describe what outcomes are valued and then directly asking if they are likely to be achieved. For example, Intensivist 17 said:

The prepared family would share what the patient was capable of doing before the critical illness, what they enjoyed doing, and then the question would be, how likely is it we will get back to that situation?

Discussion

In semistructured qualitative interviews, intensivists expressed tension between a perceived professional obligation to discuss post-discharge outcomes with surrogates and uncertainty in their ability to accurately predict those outcomes. Lack of contact with ICU survivors, and overly optimistic expectations for recovery among ICU surrogates, were identified as barriers to discussions of post-discharge outcomes, whereas clinical experience and outpatient contact with ICU survivors were cited as facilitators. Existing outcomes research was cited as both a facilitator (by guiding understanding of patient outcomes) and barrier (due to immaturity of the field and the unknown implications of research findings for individual patients).

Intensivists' concern about their ability to prognosticate post-discharge outcomes is consistent with existing literature in oncology and end-of-life care (28, 29). However, intensivists may overestimate the need for precision when discussing post-discharge outcomes because surrogates do not perceive physician prognoses as absolutely accurate (30–33). The vast

Table 3. Role of clinical experience in discussing post-discharge outcomes with intensive care unit surrogates

	Facilitator	Barrier
Experience seeing patients after ICU discharge	<p><i>I have enough experience with discharging people and seeing them follow-up that I can make that judgment....It's based upon enough experience and seeing patients recover and then seeing them in the outpatient setting.—Intensivist 9</i></p> <p><i>I follow them after they're released from the ICU because I'm a pulmonologist, so they come to my clinic afterwards and some of them still complain about insomnia or depression.—Intensivist 23</i></p>	<p><i>As a critical care physician I have nothing to do with it [post-discharge outcomes]....You gotta understand we don't see them after discharge.—Intensivist 21</i></p> <p><i>We have a fairly narrow scope of vision in the ICU, we're thinking about in-hospital mortality, getting them out to the wards....We're not really thinking about, well is this guy going to be back to work in 6 months, no, we're never thinking about that.—Intensivist 12</i></p> <p><i>When it comes to long-term outcomes we rarely are aware of the patient's functional abilities down the line....Even if they [patient outcomes] were assessed they wouldn't make their way back to me, so my ability to calibrate my prediction there is poor.—Intensivist 17</i></p>
Experience speaking with ICU patients and surrogates	<p><i>I feel pretty confident. I feel relatively at ease. I've had lots of these types of conversations with families, some of my junior partners are uncomfortable because of the unknown.—Intensivist 20</i></p> <p><i>I'm pretty comfortable answering most of the questions, but I've been at it a while.—Intensivist 11</i></p> <p><i>Ten years into being an intensivist, I'm much more comfortable, but early in it's difficult.—Intensivist 8</i></p> <p><i>I feel relatively comfortable answering them, only because I've learned to be comfortable.—Intensivist 6</i></p>	

Definition of abbreviation: ICU = intensive care unit.

majority of ICU surrogates understand that uncertainty is unavoidable and want physicians to provide prognostic estimates even when uncertainty is high (34, 35). Therefore, uncertainty should not be a barrier to discussing likely post-discharge outcomes with patients and their families. In this context, stating that the situation is highly uncertain and providing a range of possible outcomes, such as best case, worst case, and best-guess estimates, may be sufficient and could be an important step toward meeting a surrogate's need for information (36).

This study demonstrated intensivist discomfort in discussing post-discharge outcomes as opposed to current patient status, ICU procedures, or in-hospital survival. Discussions about post-discharge outcomes are different because many intensivists do not witness these outcomes. The extent to which research on post-discharge outcomes of ICU survivors mitigates this challenge is unclear, whereas lived experiences, whether

speaking with families, or seeing ICU survivors in the clinic, were consistently cited by our sample as helpful. Requiring critical care trainees to observe and practice family meetings, and to interact with ICU survivors after hospital discharge (in both in- and outpatient settings), may help to provide context and experience to assist in discussions with surrogates. Although high-quality research on post-discharge outcomes is essential to planning for the health-care needs of ICU survivors at the societal level and to understanding the physiological mechanisms driving recovery, it may not have a strong impact on clinician comfort in discussing the expected outcomes of individual patients.

The questions intensivists want surrogates to ask regarding return to valued activities require patients to have engaged in advance care planning with their families before ICU admission. Therefore, critical care clinicians should be strong advocates for advance care planning in the outpatient

setting. Advance care planning is not simply documenting an individual's treatment preferences in a hypothetical future health state, but preparing families to make decisions that are consistent with that individual's values (37, 38). The desire expressed by intensivists for families to ask about the likelihood of returning to valued activities suggests endorsement of permitting patient preferences to impact treatment decisions—an essential element of shared decision-making. The American College of Critical Care Medicine and the American Thoracic Society have endorsed shared decision-making when defining overall goals of care and making major treatment decisions that may be affected by personal values, goals, and preferences (16).

Although many patients have not formally documented their wishes before ICU admission, they often have informal conversations with surrogates about their priorities in the event of serious illness (39, 40). Available tools, such as video

Table 4. Role of research in discussing post-discharge outcomes with intensive care unit surrogates

	Facilitator	Barrier
Available research on functional outcomes	<i>There is various disease data published in terms of how people do at 3, 6, 9, 12 months down the road based upon what they're like when they leave the unit.—Intensivist 1</i>	<i>Functional recovery, we don't know so much. We know discharge dispositions but we don't know functional recovery very well, unfortunately.—Intensivist 9</i>
	<i>For many of the clinical syndromes there are data that can help guide that [discussion].—Intensivist 5</i>	<i>[We] don't have very refined tools for understanding cognitive and physical functioning after 6 months, so we don't measure it very well and we don't understand it very well.—Intensivist 5</i>
	<i>If they required multiple techniques for life support I think their chances of being home and living independently are probably about, if I remember the literature, about 9% or 11% or so, it's about 1 out of 10.—Intensivist 10</i>	<i>Only over the last several years have we even been paying any attention to it [mental health outcomes], so I just don't feel like I have a good handle on how people feel after they leave the ICU.—Intensivist 2</i>
Ability of research to inform discussions about individual patients		<i>The long-term effects of a prolonged ICU stay—I know the data is there and I've read it, it's just I don't know how I can attribute that to each individual patient.—Intensivist 14</i>
		<i>Even the outcome studies we have—there are so many confounders that can be in the situation with the patient, you don't have specific studies for this type of patient with this type of injury every time.—Intensivist 8</i>
		<i>So you can know groups of patients, but I don't know that you can predict the single patient.—Intensivist 19</i>

Definition of abbreviation: ICU = intensive care unit.

decision support and the Facilitated Values History, can help ICU surrogates make authentic decisions for incapacitated loved ones based on these informal conversations (41, 42).

This qualitative study is subject to limitations as outlined herein. We interviewed a small sample of intensivists from academic hospitals in the United States, and our results may not be generalizable either to other care settings or to other clinicians in the ICU. By virtue of having volunteered for this research, participants may have been disproportionately knowledgeable or interested in outcomes research. However, we purposefully recruited a diverse study population that included ICU physicians with various degrees of experience and

divergent preexisting views on end-of-life care across 16 states and 20 hospitals. Common themes emerged despite treating patients of diverse ages, acuity, and distributions of comorbidities in disparate geographic locations.

For ICU surrogates to engage in informed shared decision-making they must understand the likely outcomes of critical illness. Intensivists feel obligated to provide surrogates with this information but many expressed doubt in their ability to predict these outcomes with sufficient accuracy. However, high levels of accuracy may not be required for shared decision-making because surrogates expect and accept the inherent inaccuracy of prognostic estimates. Therefore, discussing expected post-

discharge outcomes in a way that acknowledges uncertainty should be a standard part of conversations with families in the ICU. For these conversations to happen consistently, they need to be taught, practiced, and consistently modeled for trainees, so that junior intensivists have the experience their senior colleagues cite as essential to their comfort. ■

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