Unplanned Admission to the ICU

A Qualitative Study Examining Family Member Experiences

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BACKGROUND: Transfers to the ICU from acute care are common, and it is essential to understand how family members of critically ill patients experience these transitions of care.

RESEARCH QUESTION: Can we enhance our understanding of family members' experiences during hospital stays complicated by a patient's unplanned admission to the ICU?

STUDY DESIGN AND METHODS: Qualitative interviews were conducted with family members of patients were transferred from acute care to the ICU at a level I trauma center in Seattle, WA (n = 17). To organize data, we used thematic analysis, coupled with a validated conceptual model of clinician-surrogate communication.

RESULTS: Drawing from a validated conceptual model, we used two domains to frame our coding: "information processing" and "relationship building." Within information processing, we coded information disclosure, sensemaking, and expectations; within relationship building, we coded emotional support, trust, and consensus and conflict. Family members wanted timely, accurate information about the patient's condition both during and after transfer. An unplanned ICU admission was a stressful event for family members, who looked to clinicians for emotional support. Developing trust was challenging, because family members struggled to feel like integrated members of the medical team when patients transitioned from one setting to another.

INTERPRETATION: Family of patients who experience an unplanned ICU admission want high-quality communication both during and after a patient's transfer to the ICU. This communication should help family members make sense of the situation, address unmet expectations, and provide emotional support. In addition, interventions that foster family-clinician trust can help family members feel like integrated members of the care team as they face the challenge of navigating multiple different environments within the hospital.

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Transfers from acute care to the ICU are common^{1,2} and often involve patients at high risk of death.³⁻⁶ With the widespread adoption of rapid response teams,^{7,8} patients who experience clinical deterioration on the acute care floor often begin receiving intensive care immediately. Many clinicians are accustomed to handling these transitions of care; however, for family members of these patients, this chain of events is unexpected and alarming.

Any hospitalization can be stressful for patients and their family members.⁹ This stress is amplified when the patient's condition worsens, resulting in an admission to the ICU. There are abundant data regarding the long-term effects of an ICU stay on family members of critically ill patients that include the development of a post-intensive care syndrome marked by adverse psychological outcomes¹⁰⁻¹³ and complicated grief.¹⁴ Although we know a great deal about how an ICU stay can affect family members, we know little about how the patient's pathway to the ICU factors into a family

member's overall experience. Existing data suggest that, compared with the family of patients who are admitted to the ICU from the ED, family of patients who are transferred to the ICU from acute care report lower satisfaction with care and quality of dying.¹⁵ Differences in chart-based indicators of palliative care also suggest that these family members receive less communication, including fewer family conferences and fewer discussions about prognosis.¹⁵ Family members' perceptions about the quality of care in the ICU may reflect not only their feelings about the ICU stay but may also be influenced by experiences before and after ICU admission.

To enhance our understanding of family member experiences related to an unplanned admission to the ICU, we conducted qualitative interviews with family members of patients transferred from acute care to the ICU. We anticipated identifying deficiencies in communication before, during, and after patient transfer.

Methods

Design and Setting

In this qualitative study, we conducted semistructured interviews with family of patients who were transferred from acute care to the ICU after a clinical deterioration. All participants were recruited in 2015, from a level-1 trauma center in Seattle, WA, where patients could be transferred to the following ICU services: medical, cardiac, surgical/trauma, or neurocritical care. This project was approved by the institutional review board at the University of Washington.

Participants

Eligible family members were ≥ 18 years of age and English-speaking. We identified eligible family members by screening each ICU census for patients who were transferred from acute care to the ICU, excluding patients whose acute care or ICU stay was < 24 hours. Family members were approached at the patient's bedside, and written informed consent was obtained. Consent for medical record review was provided by patients when they retained decision-making capacity or legal-next-of-kin when they did not.

Data Analysis

An interview guide was developed by a multidisciplinary group of clinicians and researchers with expertise in the care of patients with critical illness, use of qualitative research methods, and evaluation of patient- and family-centered outcomes.¹⁶⁻²³ Each interview began with an open-ended question: "Walk me through what happened to [patient], starting from when s/he decided s/he needed to go to the hospital, to being on the floor, to transferring to the ICU. What happened and how were you involved?" Prompts and probes focused on the sequence of events before, during, and after a patient's ICU admission and explored communication between family members and clinicians on acute care and in the ICU and the family members' understanding of how the patient's medical condition evolved during the hospitalization. These prompts and probes were adapted for each family member to explore the issues that seemed most salient to them.

In-person interviews with family members were conducted in a private location. Interviews were conducted by one investigator (A. L. J., who is a pulmonary and critical care physician who was not involved in the care of study participants) between March and August 2015. Interviews were audio-recorded and transcribed by a professional transcriptionist. In one case, the audio-recording failed, and field notes were used. Transcripts were analyzed as interviews occurred, with careful attention to identification of unique elements of the family member experience. Interviews were conducted until the interdisciplinary team concluded that new themes were no longer occurring in the data.^{24,25}

Two investigators (A. L. J. and M. R. H., one with a medical background, the other with a background in communication) read all the transcripts to gain an understanding of families' experiences. They then selected 3 interviews from respondents with differing profiles (eg, family member relationship to patient, mechanism of clinical deterioration) to facilitate development of a codebook. Using thematic analysis, A. L. J. and M. R. H. independently coded three more transcripts, refining the codebook in an iterative fashion. Consensus was used to reconcile differences, with 100% agreement reached. Infrequent or overlapping codes were removed, and the codebook with example quotes was shared with an investigator who was unfamiliar with the transcripts (R. A. E.) for additional revision.

To build the codebook, we used domains from a previously validated conceptual model of clinician-surrogate communication.²⁶ The theoretic principles set forth by Torke et al²⁶ aligned well with our data, and we simplified conceptual definitions and structured our codebook using existing domains. Independent reevaluation of a revised codebook with quote examples was done with 90% agreement on a dominant code among all five investigators. Using this version of the codebook, two investigators (A. L. J., M. R. H.) coded all transcripts. Atlas.ti textual data analysis software (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used for our analysis.

Results

Thirty-nine eligible family members were approached, and 17 of them (44%) participated. Of the 17 participants, 77% were women. Most family members were white and non-Hispanic and included spouses (29%), adult children (29%), parents (24%), or siblings (18%). The average age of the 16 participants who provided this information was 55 years. Fifteen family members agreed to provide educational information, of which one reported a high school diploma or equivalent, seven reported some college or trade school, three had a four-year college degree, and four completed graduate or professional school.

Drawing from the conceptual model developed by Torke et al,²⁶ we used “information processing” and “relationship building” domains to organize our coding. Each domain is comprised of several different elements. Within the information processing domain, we coded information disclosure, sensemaking, and expectations; within the relationship building domain, we coded emotional support, trust, consensus, and conflict (Fig 1). Representative quotes reflect definitions developed for each code within these broader domains (Table 1).

Information Processing

Information Disclosure: Family members noted difficulty getting information about the patient’s condition, particularly during a period of clinical

deterioration. Although family members acknowledged the importance of prioritizing the patient’s care, they also expressed a desire to be informed and involved during the transition process:

“One of them could have at least explained what’s going on...they were talking amongst themselves. I couldn’t understand everything...I felt, at that time, one of them could have said something to me. Because they did ask who I was and I told them. But that’s about it, and then they were talking amongst themselves.” [Study ID No. 008]

Family members were upset when they did not receive updates about a change in the patient’s status, found out information from other family members, or in some cases, were not informed at all. As one family member noted:

“Coming to the hospital, to the regular floor, having not been notified that he was being switched [to the ICU], that was disturbing.” [Study ID No. 006]

This need for information extended to the ICU, where family members expressed a desire to have clinicians help them understand what happened after an unplanned ICU admission:

“If that nurse had done a little bit of, ‘Okay, he’s stable for the moment. Let’s talk about what happened and what probably is going to happen next.’ Just to make a point of helping the family step back one step, ‘This is going on. What questions do you have?’” [Study ID No. 002]

Sensemaking: As a patient was being transferred to the ICU, family members struggled to make sense of what was happening. They relied on information from clinicians and made their own assessments based on events happening in the environment. Reactions to the unexpected transfer of their loved one from acute care to the ICU differed across family members. For some, the transfer portended a negative change in the patient’s hospital course:

“The minute your family member gets moved from a regular floor to intensive care, it heightens your awareness. Your bells and whistles immediately go off. You go into defense mode because now your loved one’s life is in jeopardy...This is, ‘We’re not playing.’ You know?...it just means that...this is serious, and I think it puts any person’s mind into a different mindset.” [Study ID No. 009]

For others, a move to the ICU was met with relief, based on a perception that clinicians in the ICU were more available to their loved one than clinicians on acute care. Still others struggled to understand what the ICU admission meant for their family member, both in terms of the patient’s medical condition and in terms of who would be caring for the patient. A transfer from acute care to the ICU added complexity to an already confusing situation:

Figure 1 – Codes and associated domains, adapted from Torke et al.²⁶

TABLE 1] Family Member Experiences During a Hospital Stay Complicated by an Unplanned ICU Admission: Codes, Definitions, and Example Quotes

Codes	Definitions	Example Quote
Information processing		
Information disclosure	Getting the information from clinicians	We definitely had questions, but it was like, "Okay, my brother's life is at risk here"...I think they did their best to give us information, when they could, but their focus was there...I think somebody else who knew the ropes...If they could just get some information and let us know that, I think that would have been helpful. [Study ID No. 005]
Sensemaking	Making sense of the situation based on information from clinicians or from events happening in the environment	When you get the phone call from a doctor going, "Oh, hi, this is Dr..." I freaked out. Because it's not the nurse calling you, right? It's the doctor, and doctors really don't talk to anybody unless they have to, so that was...like, "Oh my gosh, what's going on?" When he told me she was moving to the ICU...I can't really tell you exactly what my emotions were. I know I was scared, and I was trying to figure out what was going to happen. [Study ID No. 015]
Expectations	Expecting things to go a certain way based on an understanding of the patient's illness	But I just didn't even think of that part – "Oh, she's done with her surgery. She's on the floor. She's good now." You know?...It didn't pop into my mind that something could happen that she'd have to move to ICU. [Study ID No. 008]
Relationship building		
Emotional support	Receiving support from clinicians during an intense experience for family members	I appreciate the empathy. I mean everybody has been immensely supportive. We feel as you're viewing my Mom more than just a number and a piece of paper; that you guys get that this is my precious mother. [Study ID No. 009]
Trust	Knowing clinicians are dedicated to the patient and their family members	That's been one of the hardest parts of the experience...every floor that you go to, you usually have different doctors. You definitely have different social workers, different nurses. So, you almost have to start all over again, and that's really frustrating. [Study ID No. 011]
Consensus and conflict	Working together to make decisions that advance the patient's care	Well, at some points, I wasn't sure that they were communicating what I was telling...Like, I would tell one person...I had to repeat it. And I didn't feel the communication was as good as it could have been. I know they're trained; I know it. But I knew him better, and I felt like they weren't listening to me. [Study ID No. 006]

Codes and definitions adapted from Torke et al.²⁶

"This idea that there are ICU doctors and acute care floor doctors, that's all new to me...there were always doctors coming in, saying 'Hello. I'm going to be taking care of [patient] for the next 24 hours.' And then, 'Bye.' And then the next doctor would come in...just that kind of disorientation of not knowing." [Study ID No. 001]

Expectations: Family members presumed the patient's hospital course would go a certain way, based on their understanding of the patient's illness, and an unplanned ICU admission contributed to unmet expectations. Most

family members shared a sense of surprise related to the ICU transfer:

"Having no foreknowledge that things would happen the way they did, or a possibility of it...you're like, 'Oh, a couple of days in here and we'll go home.' And then it was like one thing after another was being discovered." [Study ID No. 003]

Expectations shifted after an unplanned ICU admission, as family members began to acknowledge the potential

for repeat ICU admissions and delays in discharge from the hospital:

"It's the first time I had seen rapid response. And it's sad; now it's gotten normal, but at that point, I guess I had in my mind that when you progressed...you're going to get better and better...I didn't really understand what a roller coaster it was – that you would get better and worse and better." [Study ID No. 011]

Relationship Building

Emotional Support: Family members described how the stress of hospitalization was exacerbated by a transfer from acute care to the ICU. During high acuity situations, such as a rapid response, family members looked to clinicians for reassurance:

"They could have said, 'We're going to try and figure out what's going on. We are going to figure this out.' That little bit of comfort would've been great. But everybody was scared. It's like it scared everybody." [Study ID No. 006]

After a transfer from acute care to the ICU, simple gestures from clinicians demonstrated emotional support and helped establish rapport. One family member talked about how something as simple as checking in on a patient meant a great deal:

"Some of the staff...like a day or two later...dropped by to let him know like, 'Hey, we're so glad that you responded and you're back.' And that kind of level of interaction, it was really cool and was really touching." [Study ID No. 005]

Trust: It was important for family members to feel like they could rely on the medical team and that clinicians were dedicated to the patient. This sense of dedication was lacking when family members did not feel their concerns were being acknowledged:

"And it was a tough night. I think the worst thing that happened was he kept asking for his heart medications and the people would leave the room and say, 'Oh, yeah, I'll go look into that.' And nothing happened. And then, by about four o'clock in the morning, he was really feeling poorly." [Study ID No. 003]

Fragmentation of care also affected family members' sense of trust. There was limited understanding of the fact that acute care clinicians did not follow patients into the ICU, where the "closed" ICU model seemed to contribute to a lack of connection:

"The [acute care] floor was completely out of the picture. Like, they never existed. So, the doctor that I had been talking to, for ten days...it's like, evaporated...that's been one of the things that has confused him. He's trying to bond with somebody, and there's a revolving door of doctors and nurses...there's just no opportunity to build trust with somebody." [Study ID No. 002]

Consensus and Conflict: To achieve consensus and avoid conflict, family members wanted to work with clinicians to make decisions that advanced the patient's care. The inclusion of family members in the patient's care deescalated conflict during high-stress situations:

"So, he told her, directly at least twice that he was having pressure because he didn't have any heart medicine. That other team that came in...they actually heard me. No one else had actually listened to me until they went, 'That's good to know. We needed to know that.'" [Study ID No. 003]

Family members of transferred patients were able to draw comparisons between their involvement in decision-making across different hospital settings. For some family members, inconsistent approaches to inclusion in the patient's care promoted discord:

"It felt like more that you weren't part of the care plan...The doctors would pass through, but the nurses would head them off...they would go talk to them and then come back and repeat it to me. And that's not how it is down in critical care, they make you a part of that...I felt like they were just blocking you from trying to have any more improvement for his care, and I was getting pretty frustrated." [Study ID No. 016]

Discussion

Despite the frequent occurrence of unplanned ICU admissions,^{1,2} little information exists about how these admissions affect family members of critically ill patients. This study provides important insights into the experiences of family members faced with the clinical deterioration of a loved one. Family members reported deficiencies in communication and care related to two key domains: information processing and relationship building. Within the domain of information processing, family members identified specific challenges related to information disclosure, sensemaking, and managing expectations. Within relationship building, family members described a need for emotional support, trust, and consensus building.

Before, during, and after a patient's transfer from acute care to the ICU, communication with family members about the patient's condition should be a priority for clinicians.^{27,28} However, providing high-quality communication during a time-sensitive, high-acuity situation such as a rapid response can be difficult. Although family members understood that during these situations the clinicians' primary focus was the patient, they expressed a desire to receive critical information both during and after transfer. Engaging family members in high-stakes conversations during rapid response events is feasible,²⁹⁻⁴⁰ and inclusion in

conversations about the reasons for clinical worsening and need for transfer should be the norm.

One approach to involving family members in the transfer process might include a bedside handoff in the ICU, where both acute care and ICU teams are able to review the events that preceded transfer with family present. Family involvement during the handoff process has several potential benefits, because family members may be able to provide a unique perspective about the patient's clinical course and the events leading up to transfer.^{41,42} Inclusion in the transfer process could help family members process the events leading up to the ICU admission; for family members who did not feel heard during the transfer process, involvement during handoff could provide an opportunity for them to express their concerns. The use of electronic portals^{43,44} to facilitate clinician-family communication also offers a promising approach to improve family members' experiences related to an unplanned ICU admission. Importantly, when family is not present, mechanisms should be in place to notify them of a patient's transfer.

For family members of patients who are admitted to the ICU from acute care, prior expectations about the patient's hospital course may no longer be realistic. Managing expectations is a key component of interventions designed to transition patients successfully from the ICU to the acute care floor.⁴⁵ For family of patients transferring to the ICU, managing expectations is equally important. By discussing the ICU admission in the context of the patient's preceding hospital stay, clinicians can give family members a better appreciation of what to expect moving forward. An important driver of family member expectations is their understanding of the patient's prognosis. Conversations about prognosis are an integral component of communication with family members of critically ill patients,⁴⁶ and an unplanned ICU admission may be an important prognostic factor to consider during these discussions, particularly when the patient spent several days on acute care before transfer.⁴⁷

Establishing rapport with patients and their family members is a core component of high-quality care. For patients and family of patients who are transferred from acute care to the ICU, this can be an especially challenging time to build rapport. The siloed nature of health care within a hospital strains the ability to establish rapport with family members, and the high-volume turnover of clinicians can result in family members who have no clear

idea of who is providing care to the patient.⁴⁸ Specifically, the "closed" ICU model may have unintended consequences for family members who are attempting to build trust with clinicians on acute care.⁴⁹ A collaborative approach to patient care would be beneficial when a family member has already established a relationship with an acute care clinician before ICU admission.

This study has several limitations. First, we recruited participants from a single center, which may limit generalizability. However, the attributes of our center are very similar to other, large academic environments. Second, selection bias is also a concern, because some family members may have declined participation for reasons that could have affected our findings. Fortunately, we were able to identify a common experience shared among participants. Third, interviews with family members were conducted after the patient's transfer to the ICU, making it challenging to be certain of the patient's awareness of what was occurring during the transfer and how that awareness may have affected the family members' experience. Our findings illustrate that, even for patients who were communicative, transfer to the ICU was a challenging experience for family members, and opportunities for improved communication exist regardless of the severity of illness. Fourth, all patients were alive at the time of our interviews with family members. Our findings therefore may be less applicable to the experiences of bereaved family members. Finally, we recognize that there are multiple stakeholders involved in unplanned ICU admissions; additional studies are planned to understand the perspectives of patients and acute care and ICU clinicians.

The clinical deterioration and transfer of a patient from acute care to the ICU is a stressful experience that affects family members' perceptions of care and communication throughout the remainder of the patient's hospitalization. Family of patients who experience an unplanned ICU admission want high-quality communication both during and after a patient's transfer to the ICU. This communication should help family members make sense of the situation and should address unmet expectations and provide emotional support. In addition, interventions that foster family-clinician trust can help family members feel like integrated members of the care team as they face the challenge of navigating multiple different environments within the hospital.

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