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## Exploring the process of information sharing in an adult intensive care unit: An ethnographic study

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### Abstract

Information sharing, a component of patient and family engagement (PFE), is an important process that may contribute to intensive care unit (ICU) quality of care. Yet, virtually no studies explore how the process of information sharing unfolds in the ICU from the interprofessional team and family member perspectives. To better understand the process of information sharing, we conducted ethnographic fieldwork in a 20-bed medical ICU, focusing on behaviors and interactions of the interprofessional team and family members (May 2016 – October 2016). We completed 17.5 observation hours, 6 shadowing sessions, and 12 semi-structured interviews with 17 total participants. We used thematic content analysis and iterative inductive coding to identify three themes about the information sharing process: 1) family factors (health literacy and past experience with the ICU environment) influence information sharing; 2) clinicians strategies can support engagement in the process of information sharing (assessing families' need for information, understanding a families' hope, using rounds as an opportunity for information sharing); 3) the process of information sharing allows for trust building between families and the ICU team. Our findings suggest that information sharing is a crucial process that may serve as a catalyst for effective patient and family engagement in the ICU.

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**Data sharing:** Given the single site nature of our study and the risk of identifying participants, we are unable to share the final dataset.

## INTRODUCTION

In the last ten years, an increased emphasis on improving the patient experience has led to a commitment to engaging patients and families in care, specifically in the intensive care unit (ICU).<sup>1,2</sup> Previous observational studies on patient and family engagement (PFE) has shown that increased engagement is associated with positive outcomes such better patient-reported health and effective communication,<sup>3</sup> clinical decision making and patient safety.<sup>1,4</sup> Internationally, this has led to a clear commitment to engage patients and families in all aspects of healthcare, including the development of research questions and the grant review process.<sup>5</sup> Vital to engaging patients and families is the back-and-forth flow of information between the clinicians responsible for care (e.g. the interprofessional team) and the patients and families receiving care.<sup>6</sup>

In its broadest terms, information sharing is defined as a bi-directional flow of information between a clinician and the patient and family.<sup>6</sup> As such, information sharing serves as a key facilitator through which collaboration and participation can be achieved.<sup>6</sup> Yet, the nuances of how information sharing occurs in the ICU, its role as an independent dimension of PFE in practice, is not well described. Most of the prior work either focuses on family members and a single profession (i.e. most often nurses) or uses only one qualitative method and is unable to capture the information sharing process comprehensively. For example, early work interviewed families and nurses and found families highly valued receiving information about their loved ones from the nurses.<sup>7</sup> But this study did not include other interprofessional team members that are involved in daily discussions with families in the ICU. In another qualitative study, family member and staff interaction were observed in the ICU but only family members were interviewed; they found that clear information from the ICU staff was an important starting point for family-staff relationships in the ICU.<sup>8</sup> More recent studies that focus on information sharing have examined it as it relates to end-of-life decision making in the intensive care unit.<sup>9-12</sup> It is rare in the current literature to examine information sharing in the ICU (that is not related to end-of-life), and to include both family and interprofessional team members perspectives using multiple qualitative methods.

The lack of data regarding the perceived value of, and commitment to, information sharing from both the family and interprofessional team perspective is a significant gap in knowledge as it prevents enhancement of PFE in the ICU more broadly.<sup>13</sup> Understanding and identifying how families and the interprofessional team perceive and engage in the information sharing process comprehensively is needed to inform future initiatives to enhance patient and family engagement in the adult ICU.

The purpose of our study was to explore the process of information sharing in the ICU, focusing on behaviors and interactions among family members of ICU patients and the ICU interprofessional team in a single medical ICU over 6 months. We focus on the interprofessional team (including nursing, medicine, respiratory therapy, and chaplain) since these team members are most likely to interact with family members during day-to-day ICU care.

## METHODS

This study was an ethnographic study; we used multiple, sequential, qualitative methods as they are best suited to understand complex processes and phenomena, like the process of information sharing among family members and the interprofessional team.<sup>14</sup> More specifically, the multiple sequential qualitative methods we used were observation, shadowing and semi-structured interviews<sup>9</sup>.

### Setting and Participants

We conducted ethnographic fieldwork in a 20-bed medical ICU in an academic medical center in the United States from May 2016 – October 2016. This ICU was a closed ICU (i.e. care was led by board certified critical care physicians).<sup>15</sup> Prior to data collection, we met with the ICU leadership to garner support and posted fliers in the ICU explaining the study. We recruited interprofessional team members and family members as participants; we did not include patients as many were mechanically ventilated and were unable to engage in continued dialogue. Participants were identified primarily via convenience and snowball sampling techniques during our in-unit observations and shadowing and by identifying other participants from shadowing and interview participants.

Our inclusion criteria for ICU clinicians were that they: 1) worked as permanent, full-time employee at the study hospital; 2) were licensed or certified in their respective profession; and 3) cared for ICU patients. Family member participants were included if they: 1) were a family member of an ICU patient on the study unit, and 2) had interacted (at any time) with members of the ICU team. We excluded ICU clinicians that were in training (i.e. medical students, student nurses or respiratory therapy students), any travelling or agency clinicians, any clinicians still on orientation in that unit as well as any first-year residents. We aimed to recruit clinicians from different professions (at least 2 individuals from each profession) and experience levels to shadowing and interviews to get as many perspectives as possible. To determine final sample size for shadowing and interviews, we conducted preliminary analyses while data collection was ongoing to determine data adequacy, assessment of redundancy and thematic saturation.

### Ethical considerations

We did not receive signed or verbal informed consent from participants for observation; clinicians were informed of the study beforehand and had the opportunity to opt-out or request that we leave. During data collection for shadowing and interviews, verbal informed consent was received from participants. Shadowing and interview participants received a small incentive for their participation (\$40 gift card for shadowing; \$20 gift card for interviews). The study was approved by the University's Institutional Review Board (HUM00109191).

### Data collection

Data collection was coordinated with the unit's leadership to minimize ICU staff burden each shift (i.e. limiting shadowing when there were multiple students and/or orientees in the unit). Three individuals collected the observation, shadowing and interview data—a

PhD prepared ICU nurse (DKC), a nursing doctoral student (EMB) and an undergraduate nursing Honors student (MRW). EMB and MRW conducted the observations, EMB and DKC conducted shadowing experiences and DKC conducted all interviews. All training for qualitative data collection was provided by two authors (DKC and MM).

**Observation.**—We began with in-unit observations and conducted 17.5 hours of observations in the ICU. Each observation lasted two to four hours to gain insight into the nature, type and frequency of patient/family and ICU interprofessional team interactions. Two observers were present during each observation and each observer recorded hand-written unstructured field notes that were subsequently transcribed for data analysis. Observers debriefed after each observation discussing what was learned about the information sharing process in the ICU.

**Shadowing.**—We shadowed six ICU clinicians (2 nurses, 2 respiratory therapists, and 2 Pulmonary/Critical Care fellows). Shadowing is a specific type of observation where a study participant is closely followed for several hours by one research staff to learn more about their usual activities, behaviors, actions and interactions.<sup>14</sup> Family members were not shadowed due to their involvement with only a single patient. Each shadowing session lasted three to four hours in length and allowed the observer to gain a more focused view of the information sharing process from each profession's perspective and workflow. We were able to examine and ask follow-up questions, using the "think-aloud" method<sup>16</sup> to elicit more information than could be gained through simple observation. Observers took written unstructured field notes, noting the ways that the interprofessional team members interacted with family members in the ICU. These notes were then transcribed verbatim and included in our data analysis.

**Interviews.**—We completed 12 semi-structured interviews each lasting roughly one hour. We interviewed eight ICU clinicians (3 nurses, 2 physicians, 1 chaplain, 2 respiratory therapists) and four family members. These interviews were conducted in-person (n=10) or via BlueJeans, a digital video-conferencing platform (n=2), and were intended to explore perspectives on the importance and process of information sharing in the ICU. Using data from the observations and shadowing sessions, we were able to follow-up on specific encounters, such as family participation in rounds, during interviews to help explain the behaviors observed and the relationships among those behaviors. We also used our observation and shadowing data to inform our interview guide development iteratively. Interviews were audio recorded and transcribed verbatim. The interview guide is included as Supplemental Online material.

## Analysis

We used thematic content analysis and iterative inductive coding to analyze the observation, shadowing, and interview data.<sup>17</sup> Initial data analysis occurred concurrently with data collection and themes and issues were discussed during weekly team meetings. Discussion of identified themes, written analyses, and memos helped to identify particular topics for follow-up in shadowing and/or interviews (i.e. identify topics from observations and shadowing to then address in the interviews). Our preliminary analysis and team meeting

discussions allowed us to identify that we needed additional nurse interviews as we had not yet reached thematic saturation; thus, we conducted 3 nurse interviews instead of 2 as initially planned. Multiple researchers were involved in data analysis (DKC, EMB, EAM, MRW); the team collaboratively applied an analytic approach to sort, sift and think through preliminary key topics and themes.<sup>18</sup> Each researcher was responsible for reading a specific data element (i.e. field note from observation or shadowing or interview transcript), summarizing what they learned from that data element and then identifying questions for further discussion and follow-up in a memo. The same researcher then identified key quotes (from interviews) or key interactions in text (from observations and shadowing) and began to identify possible topics or codes. Different researchers reviewed different data elements so that the topics identified originated from diverse researcher perspectives. These initial topics formed the basis of our preliminary codebook. Once the preliminary codebook was developed, we met as a group (EAM, EMB, DKC, NW) to discuss the codebook and further refine it. Then, one individual (EAM) coded the data using topics and codes identified from several (EAM, EMB, DKC, MRW, NW) researcher's analyses. All data were managed using NVivo 11 qualitative software.<sup>19</sup>

## RESULTS

Information sharing was consistently identified as a key aspect of ICU care. Interprofessional team members talked to families about plans of care and the current status of the patient, while families asked questions of the clinicians about plans of care, and provided information about their family members. But there was variability in how and to what extent interprofessional team members and family members engaged in the process. In the following section, we describe the three themes we identified in our data about the process of information sharing: 1) family factors (i.e. health literacy and past experience with the ICU environment) influence the information sharing process, 2) clinicians strategies can support engagement in the process of information sharing (i.e. assessing families' need for information, understanding a families' hope, using rounds as an opportunity for information sharing) and 3) an outcome of the information sharing process was trust- and relationship- building between families and the ICU team. See Table 1 for theme definitions and illustrative quotes.

### Theme 1: Family factors influence the information sharing process

Family members were identified as important in the information sharing process between ICU clinicians and families. For families, health literacy – the degree that families were able to understand health information – affected the information sharing process, as well as families' past ICU experience.

**Health literacy**—Health literacy is defined as “the degree that individuals have the capacity to obtain, process and understand basic health information”.<sup>20</sup> Family members and clinicians both described how health literacy affected the information sharing process. While it was not explicitly identified as a barrier to information sharing, both parties recognized that it inherently influenced the information sharing process. A family member described

the importance of having the team break things down for her in a way that helped her to understand,

“[The doctors] broke down and explain[ed] about what this disease is. The one doctor even...printed us off pamphlets about it and stuff and...they break things down in detail of what’s going on. I mean, I don’t understand everything they say, but you know...I usually get it, what they talking about.”—*Family Member*

One physician explained that adapting how information is delivered based on family members’ health literacy is a vital part of the information sharing process,

“So I try to gauge where they are in the spectrum and then talk at their level, both to give them the respect that they deserve, because no one wants to be talked down to by the doctor...You know that that’s not gonna work...but at the same time...If you’re completely confused and you have no idea what I’m talking about, that’s not gonna be beneficial either...Like help me find your level, and I will talk to you at your level. There are some family members that are very articulate, and they know things...They’re very up on all their medical knowledge and the drugs and everything else, and there are other family members that...You say stuff like ‘protein,’ and they’re like, you know, ‘What does this have to do with steak? You really have to like start...you know, start from scratch...And I think it’s important to judge that and, again, if you have multiple frequent conversations, it’s way easier to judge that than [if] you’re coming in at one conversation.”—*Physician*

However, gauging the health literacy of a family was not the sole responsibility of the clinicians directly involved in patient care (i.e. nurses, physicians, or respiratory therapists). Recognizing it as a challenge for families, the chaplain described bridging the health literacy gap as a priority for them,

“Other things I do is facilitate the communication, make sure families understand what the docs are saying, make sure the docs understand what the families are saying because they speak different languages.”—*Chaplain*

**Past experience with the ICU environment**—In addition to health literacy, family members’ comfort with the ICU through past experience influenced the information sharing process. Clinicians recognized that a family’s reaction to the current ICU admission was likely related to past experiences. When describing family participation, one nurse reflected,

“I think some of that comes with the level of comfort of the family...So are they accustomed to seeing their loved one critically ill? Is this not their first rodeo? You know, they’ve been down this road before, or is this something new and completely shocking...So there’s kind of that decision-making tree branch...how accepting the family is of the environment. Are they intimidated by the machines? Are they intimidated by all the IV’s? Are they intimidated by the leads?”—*Nurse*

One family member identified herself as someone who is more willing to participate in team discussions citing her past hospital experience as a contributing factor,

“I do [feel comfortable in rounds]. Now part of that is, I’ve just been doing this for a long time...they started that a while back in Ped[iatric]s too, in making sure to

include the family in the rounds and the discussion and the plan for the day...So, I have been doing this for a while..."—*Family Member*

## **Theme 2: Clinician strategies can support engagement in the process of information sharing**

Clinicians described three strategies they use to support information sharing. For ICU clinicians the ability to assess family members' level of engagement for information was a thoughtful technique to support information sharing. Additionally, clinicians described a fear of interfering with a families' hope which placed limits on the amount of information the clinician shared. Lastly, clinicians described interprofessional rounds as a possible strategy to share information but, this was not viewed as an ideal strategy by all.

**Assessing families' level of engagement for information**—Clinicians described assessing patient and family characteristics to gauge how receptive families would be to information and then adapting their behavior accordingly. For example, a nurse described how they gauge a family's readiness to receive information,

"...I think it's a lot of nonverbal cues...So I find that if the family is kind of hedging at the door...So if their body language...you know, the arms are crossed... There's just a nervous anxious stance and a reluctance to enter the room, that's always a clue of, 'Come in. Let me show you around and introduce.' Chit chat about where you're from. Break the ice. Let's talk about a few nonmedical things here for a minute. Let's gain a rapport and get focused. Then, 'Let me explain to you what's going on here.'"—*Nurse*

A physician expressed that after meeting the families where they are, clinicians need to allow the families to identify their own level of willingness to engage,

"You've got to meet them where they are...It isn't a one-size-fits-all. So, you must be on rounds. You must stand there and listen. I'm not going to make anyone do that. They need to know they're absolutely welcome to do that, but they have to find their own level of willingness to engage."—*Physician*

**Fear of interfering with hope**—Despite the described importance of information sharing, clinicians admitted that they were hesitant to provide information if they feared it would interfere with the family's hope for recovery, which limited the sharing of honest information from clinician to family. However, this hesitancy may have been affected by a clinician's understanding of their role. A nurse explained,

"I don't want to shatter hope, but I don't want to be cruel. I don't want to be that honest, but sometimes...I really wish we could. I wish we could. 'There's nothing that we can do...Our recommendation to you is you need to stop this because...It is difficult for us to do this.' Something like that, you know? I knew one doctor...He said that...It must be nice to be a doctor. To say that, you know...I can't though. But, no. You don't want to shatter hope."—*Nurse*

Conversely, some families described wanting information even if it crushed their hope because they wanted to be prepared for the worst.

“...I’d rather for them to tell me the truth than, you know...getting hopes up for nothing, you know...so that I could prepare for the worst if I had to. I ain’t want the worst, but tell me the worst, but, you know, I’m trying to be strong and be realistic about things.”—*Family Member*

Furthermore, families reported that even though the information may crush their hope, they appreciated the honesty from clinicians.

“...Is there a possibility that he could get better, and if he does get better, what is his quality of life going to be like at that point?” And they were very honest with us and said, ‘you know, honestly we don’t think that he’ll be able to get through this hurdle to get over this infection.’ Then they said, ‘But there’s this small chance that he could, but if he does, he’s most likely going to be in a bed for the rest of his life, on a ventilator for the rest of his life,’ and they were very honest about what his life would look like, and that was the...deciding factor for my brother and I to make the decision to withdraw care because our father wouldn’t want to live like that.”—*Family Member*

**Interprofessional rounds as a strategy for information sharing**—Interprofessional rounds were identified as a way to include family members and share information due to the structure of rounds. In the study unit, interprofessional rounds occurred daily; multiple members of the patient’s care team including the physician, nurse, respiratory therapist, pharmacist and dietician participated and discussed the patient’s plan of care that day. One nurse explained how a change in hospital policy led to greater family presence on rounds:

“I think the big thing is the policy now...the general idea that families are included in rounds. And all the attendings pretty much make an effort to include them in rounds. And that didn’t happen 8 years ago...there was a time when it was kind of secretive...like back when I was working on the floor. It was kind of secretive and not inclusive and so we’ve gone beyond that. So I think the whole theory of involving them with rounds and keeping them informed helps. So that policy is something that helps.”—*Nurse*

Although interprofessional rounds could be one strategy to share information, with efforts made to invite family members to be present and participate, in practice there were differing approaches and perspectives to rounds from clinicians and family members. Family members described appreciating efforts made by the ICU team to keep them informed, especially tailoring information to the needs of the family after getting to know them better, but the family did not necessarily expect rounds to be directed towards them.

“So, the first couple of times, I guess [rounds] kind of caught me off-guard because...felt very depersonalized. It was very clinical... in my view, rounds aren’t really meant for family discussion... They do a lot of clinical discussion amongst themselves. So everyone is on the same page and knowing what’s going on and making decisions about care, but the other side of that is at least in my experience, because I was there so often and I was always standing around listening to rounds, the doctors got and everyone got really good at knowing I was going to be there.



So, if there was something new or something that I probably wouldn't understand, they would explain a little more just for my benefit...."—*Family Member*

Some clinicians felt that rounds were not an ideal strategy for information sharing. These clinicians perceived rounds to impact the ability to function and communicate as physicians. One physician elaborated,

"So family-centered rounds are nonsense. They're complete nonsense...The purpose of rounds...The purpose of communication on the physician team is to talk about the patient in the most concise, but yet most information-dense way possible... That is directly opposed in family-centered rounds, because family-centered rounds says that you should only talk in ways that families can understand, and the problem is that you can't function as physicians doing that."—*Physician*

### **Theme 3: Information sharing builds trust and helps develop relationships between families and the ICU team**

Clinicians and family members alike valued the information sharing process. Sharing information provided clinicians with an opportunity to build trust with family members and work to develop relationships. Clinicians described information sharing as a way to allow families to feel more comfortable sharing potentially important information about the patient. Specifically, one clinician stated,

"You know, even the simple thing of a handshake in the right cultural settings and just looking them in the eye and engaging them for a few seconds will start that trust building. They're more likely to ask questions if...they're included in the sharing of information. There's a lot of times a day or two later, 'Oh. Grandmother's got a drinking problem'...Sometimes that information comes out."—*Respiratory Therapist 1*

When clinicians shared unsolicited information with the families about what clinicians were doing as part of clinical care for the patient, it allowed trust to develop. One family member explained,

"Whenever they would come in to do...something, they would let me know what they were doing...I guess it kind of makes you feel included so that you know what's going on all of the time...I do remember one time I told the nurses...They were like, 'Oh, this is what we're doing,' and I was like, 'Great. I trust you'...They were like, 'Well, we just want to make sure you know what's going on, and that we're not doing anything that we really shouldn't be doing.' I was like, 'I trust you...'"—*Family Member*

Sharing information with the family about the patient's care helped to reinforce trust.

"...[family members] know who you are, they see this is a team-based approach, they see their loved ones are very sick, they see that the decision-making is not straight-forward and complex, and they realize that their loved one is in good hands, and so it creates a bond of trust."—*Physician*

However, several clinicians discussed that when all members of the ICU team did not provide the same information, it could erode the trust that had been established. Information from different clinicians could be conflicting, which could have a negative effect on trust. One respiratory therapist offered their perspective on different or conflicting information coming from,

“I just potentially worry that I’m giving...bad information and I think that’s worse than giving no information at times...When you have conflicting information, the trust deteriorates.”—*Respiratory Therapist*

In addition to helping to build trust, sharing information also assisted in developing relationships among the families and the ICU team.

“And that’s what I lean on the family the most to do. I say, ‘I’ve known them now for 3 days...you’ve known them for 35 years. Tell me what they would want. Tell me about them...tell me would this be something that they would want. What would they want to do...I know more than you about treating sepsis. You know more about your loved one and what they want and what their wishes are and what is their past medical history and all of that. So that’s the way we can utilize... You’re using me for my medical knowledge; I’m using you for your knowledge of patient X and together that’s sort of the relationship that we’re in.”—*Physician*

## DISCUSSION

In this single-site, ethnographic study in a medical ICU in an academic medical center in the United States, we conclude that family members and the ICU interprofessional team engage in the process of information sharing in various ways. From our work, we found that family factors and clinician strategies influenced the process of information sharing. Families’ health literacy and past experience with the ICU environment as well as clinicians’ ability to assess families’ level of engagement, manage expectations of hope and use rounds as an opportunity for information sharing were influential in the information sharing process. A positive result of the information sharing process was that it builds trust and assists in developing relationships among the families and the ICU team. Overall, our findings have implications for future efforts to facilitate information sharing and to improve patient and family engagement in the ICU.

Most participants described information sharing as integral to the ICU experience and ICU care. . While much of the existing literature on family engagement in the ICU has focused on active participation<sup>21,22</sup> (e.g. families providing direct patient care), our findings suggest that information sharing may be a catalyst for effective PFE in the ICU from clinician and family perspectives. While prior work has focused on information sharing as a way to facilitate shared decision-making at end-of-life,<sup>10–12,23</sup> our results suggest that working to enhance information sharing for all ICU care, not solely end-of-life care, are warranted. Further, our results have important implications for interprofessionalism. Our findings highlight that multiple different professions view information sharing as an integral part of ICU care and that it builds trust and relationships among the family and interprofessional team members. Information sharing is a process that all professions (i.e.

nurses, physicians, respiratory therapists and chaplains) participate in and one in which benefits patients, families and the interprofessional team as a whole.

Our findings reinforce prior work that explains families' desires to be informed and the high value family members place on information in the ICU.<sup>24</sup> Our data support other qualitative work that identifies information sharing as a facilitator of trust.<sup>8,25,26</sup> The finding that interprofessional rounds may not be the ideal for information sharing among patients and families is also supported in prior work.<sup>26</sup> However, given the different perspectives on the role of rounds in the process of information sharing, more investigation is needed to understand ideal times and places for information sharing from the clinician and family members viewpoints.

While we identified various strategies that clinicians used to support information sharing, there is little guidance in the literature as to how clinicians can or should do this. Notable, while clinicians assessed families for their level of engagement, this was handled in different ways by clinicians. Currently, there is little direction provided as to how clinicians can and should assess families' level for engagement. There is even less guidance about how to evaluate family members' desire for information and/or the families health literacy. Opportunities to enhance the process of information sharing could be strengthened by research that identifies a systematic way to train clinicians in their ability to evaluate families' readiness for information. These efforts could also be particularly helpful for interprofessional education; identifying strategies that interprofessional health students can employ to systematically engage in the information sharing process with families so they are better prepared for engaging with patients and families in clinical practice.

Even though we generated new insight into the process of information sharing in the ICU, we acknowledge limitations. This was a single-center study in an academic medical center. While the participants sampled from the ICU team were diverse in terms of profession, they worked in an academic medical center, which may engage families in different ways than other settings. Nearly all research team members except for two were clinicians (nurses or physicians) and thus our position in the clinical environment may have influenced the data collected, our perceptions of team interactions, and the subsequent analysis. Further, the interviewer and lead investigator was a nurse researcher (DKC) who was well-known to the unit; her position could have affected the information that was shared during interviews. Despite these limitations, our ethnographic, triangulated approach to data collection and analysis offered a robust and holistic way of assessing the information sharing process. Our study design also allowed us to dig deeper into important areas during interviews that we identified during the observations and/or shadowing experiences adding additional robustness to our results and findings.

## CONCLUSION

Information sharing is a crucial process that may serve as a catalyst for effective patient and family engagement in the ICU. Our study highlights how information sharing is a bi-directional process that assists in trust building and relationship development between the family and the ICU interprofessional team; both family factors and clinicians strategies

influence the information sharing process. Finding ways to enhance information sharing in the ICU and providing resources for both clinicians and families to support the process of information sharing are important next steps to in optimizing engagement in the ICU between families and the interprofessional team.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**

Three themes of the process of information sharing in the ICU and illustrative quotes

Theme	Description	Quote
<b>Theme 1: Family factors influence the information sharing process</b>		
<ul style="list-style-type: none"> <li>Health Literacy</li> </ul>	Family member’s ability to understand health related information.	There’s a lot of times when the language barrier from “medicalese” to . . . I can sit down and talk to somebody, and they’ll say, “Thank you for explaining this.” . . . You hear something in rounds, and you can look at their face and go, “They didn’t get that.” Potentially I have more time to sit . . . to talk to them and answer their questions and maybe explain it in a way that they can understand it. So, you know, some people have that chance. Some people have that ability to do it the first time, but you can . . . A lot of times, it doesn’t make sense when they hear it from the medical staff. (Respiratory Therapist)
<ul style="list-style-type: none"> <li>Familiarity with the ICU</li> </ul>	Family member’s comfort with the ICU environment through prior experiences.	<p>“Some of these people are here as a result of a traumatic injury or accident, and they’ve never been in a medical setting before. I have a grasp of the terminology . . . if you’re a newbie, you’re like, “What the heck are they talking about?” . . . They are going to be speaking in a way that you may not [understand], and I don’t always get everything they’re saying, but I have a pretty good grasp, and especially of [my daughter’s] particular medical problems because we’ve been down this road so many times.” (Family Member)</p> <p>Family lives about an hour away and so has been staying near hospital. This is the first time patient has been in the ICU. But another family member passed away in this ICU in a nearby room. Daughter said it’s not hard for her because she wasn’t around much when other family member was dying, but it’s hard for her brother who spent a lot of time here. So he only comes a couple days and a couple hours because it’s hard for him. (Nurse shadowing)</p>
<b>Theme 2: Clinicians’ strategies support engagement in the information sharing process</b>		
<ul style="list-style-type: none"> <li>Assessing families level of engagement</li> </ul>	Clinician’s perception of family readiness or willingness to receive information will influence how and when they deliver information.	<p>“So I tend to try and do that, and then I tend to try and ramp it up, and I just kind of look to sort of see whether they . . . understand or not . . . I try and do that a lot with many families, is I start very basic and I tell them . . . “If this is too basic, just let me know” because it’s really hard because there’s no way to judge what other people know.” (Physician)</p> <p>Medical team enter patient room to do bedside exam. After leaving room, daughter stays at bedside. Physician states to team, “we have a medically knowledgeable family member here” and then describes to team that so giving the smorgasbord [or full spectrum of options] is most appropriate. Physician continues “for the family, the decision making is tough, going back repeatedly is hard. So I watch their faces to see how they are feeling once I describe the ramifications of each discussion” (Observation)</p>
<ul style="list-style-type: none"> <li>Fear of interfering with hope</li> </ul>	Clinician’s reservation to provide information if they perceive it may impact a family member’s hope.	“The more that you educate, the more questions you can get, which is good, but then you don’t want to be honest sometimes because you’re afraid of what that’s going to do to the family . . . Shattering hope, you know . . . We’re not honest with them because we don’t want to take away that hope, whether or not that hope is false or not” (Nurse)
<ul style="list-style-type: none"> <li>Interprofessional rounds as possible strategy for information sharing</li> </ul>	Family members’ and clinicians’ perceptions regarding the use of daily interprofessional rounds as a mechanism to support the information sharing process.	<p>They were doing morning rounds, and they had gotten a new lab report that had showed that my dad had declined. He ended up having yeast in his blood, and the attending stepped away from rounds and went in personally to look at my dad. Then we had a brief conversation about what this new information meant and what his likely outcomes were. He said, “Okay. Sit with this information. After rounds, we’ll come back and we’ll have a more in-depth conversation.” And that’s what they did . . . Then I brought my brother in, and we had another conversation about it. The doctors were really good about initiating it in my situation. (Family Member)</p> <p>A patient is admitted. Family at bedside. Physician invites family to participate in rounds: “We’re gonna go over things outside. You’re welcome to come and join.” Family joins rounds. Two family members stand at door, physician to the left of family, 3 residents, pharmacist, and med student across from family, creating a circle outside of the patients’ room. (Observation)</p>
<b>Theme 3: Information sharing builds trust and relationships between families and the ICU team</b>		
	Receiving and/or providing information is a way of promoting trust between family members and the interprofessional healthcare team.	It goes back to trust . . . you know that they’re coming with a previous experience that was bad for them . . . Either it was really terrible or it wasn’t explained real well. So they come in with a preconceived type thing. They are unhappy at the previous hospital and they transfer here . . . making sure that it doesn’t happen again. So trust is a huge problem in a lot of instances . . . It’s sort of like reputation. You can spend years building it up; it only takes one instance to blow it. So, you know, when you make that mistake and you don’t explain what’s going on . . . It’s like you feel like you’ve lost a little bit of

Theme	Description	Quote
		trust and how do you prevent that... (Respiratory Therapist)

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