Final PaCER Report

“Patient and Family Experiences When Moving from the Intensive Care Unit (ICU) to a Hospital Ward”

by
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ETHICS PROPOSAL

In reflecting on the research proposal we submitted to the Conjoint Health Research Ethics Board (CHREB) for ethics approval in May 2014, we are quite satisfied with the decisions we made for recruitment, data collection and analysis. However, we do have some learnings that we will consider in future projects.

When we wrote our proposal, we thought restricting participants to Calgarians would be ideal for an internship project because it would be easier and more convenient to interview people in Calgary. However, this restriction turned out to be a limitation in recruitment. We could easily have recruited additional participants throughout Alberta from a previous PaCER study (“Understanding Patient and Family Experiences in the Daily Care of Critically Ill Patients”) and interviewed them by telephone. We did not consider this. We will be careful not to inadvertently create limitations in recruitment in future research protocols.

We had originally proposed in our protocol that we would interview participants in their homes or a place of mutual convenience. However, when our proposal was reviewed by CHREB, the reviewer insisted that we not interview people in their homes. This restriction did cause some inconvenience, as we were left to identify public places that would be convenient for people, but still ensure quiet and privacy. In some instances, the consequence of this restriction was that we could not set up a time and place of mutual convenience and we were unable to conduct the interview, or that we had to conduct the interview on the telephone. Part way through our data collection, we requested CHREB lift this restriction of not allowing interviews in people’s homes, because it was adversely affecting the collection of data, and they agreed. Those people who had interviews conducted in their homes appreciated the convenience this gave them. We learned from this experience that it is possible to re-negotiate the protocol with CHREB if necessary.

Last, in future projects we will consider including in our protocol the option of conducting telephone interviews. Although we feel face-to-face interviews are ideal, we did conduct a number of phone interviews and one Skype interview due to difficulty and/or impracticality in scheduling face-to-face interviews. Having these different options adds great value in facilitating additional interviews.

Overall, we learned it is very important to think through carefully how you plan to conduct your project, and include the ability to support this, in your proposal submission.

RESEARCH PROJECT

Recruitment

Recruitment Criteria

Patients and/or family members who had experienced patient transition from an Intensive Care Unit (ICU) to a hospital ward were recruited for this study. Both patients and family members could participate, which meant there could be more than one person from a family. Participant recruitment criteria included:

- Patient and family members self identifying as having experienced patient transition from the ICU to a hospital ward,
- Age is 18 years and over,
- Speaks fluent English,
- A commitment to take part in the SET and REFLECT focus groups and/or individual interviews.

Sample Size

This was a qualitative study with a relatively small sample size; thus obtaining a complete representative sample was challenging. However, efforts were made to obtain a diverse sample regarding types of critical care (e.g., trauma, neurology, post-surgery), hospital ICUs (Foothills Medical Centre, Peter Lougheed Centre, Rockyview General Hospital and South Health Campus) and hospital experiences (positive and challenging). Participant information was monitored by collecting contact and demographic information.

In total, 21 people participated in the study: 4 people participated in the focus groups and 17 people participated in interviews. Six people self-identified as patients, and fifteen as family members. Our sample size allowed in-depth analysis of the interview data and was sufficient to reach data saturation, the point at which no new themes or concepts emerge from subsequent interviews.

Recruitment Methods

We recruited participants in one of four ways:

1. We identified potential participants among our personal contacts through word of mouth and provided potential participants with information via the Recruitment Poster and Invitation Letters. We found that personal contacts were the most effective vehicle for recruiting participants - nine of our 17 interviewees and three of the four focus group participants were recruited through personal contacts.
2. We provided the PaCER project lead on the study "Understanding Patient and Family Experiences in the Daily Care of Critically Ill Patients," a component of "Reassessing Practices in the Daily Care of Critically Ill Patients: Opportunities to Identify and Close Evidence Care Gaps" (Ethics ID XXXXXXXXX) with the Recruitment Poster and Invitation Letters, and requested her assistance to help identify potential participants for our study from among their sample. The PaCER project lead asked potential participants to call or e-mail one of our research team members, or asked for their permission for us to contact them. Five of the 17 interviewees and one focus group participant were recruited through the PaCER project lead.
3. We provided the project coordinator for the study "Reengineering Patient Discharge from Intensive Care" (Ethics ID XXXXXXX) with the Recruitment Poster to assist her team in identifying participants. The coordinator agreed to assist us in identifying participants, and asked potential participants for their permission for us to contact them. The project coordinator provided us with the contact information for 10 people, and when we contacted these people, eight expressed interest in participating. However, due to various reasons (including continued caregiving responsibilities, busy lives and changing personal circumstances), only three ended up participating in interviews.
4. Recruitment posters were distributed in high volume locations such as hospital wards (Foothills Medical Centre, Peter Lougheed Centre, Rockyview General Hospital and South Health Campus) and care homes for the elderly. At the outset, we were sceptical about how effective posters would be at recruiting participants, and consequently were not surprised that we did not recruit any participants through the posters.

The PaCER researchers contacted interested participants by email and/or telephone to further describe the study, provide details of participant involvement and answer any questions. Potential participants were provided with Invitation Letters and the Participant Consent Form prior to participating in the study.

We made it clear to potential participants, both through intermediary contact and in the consent procedure, that we are part of an independent PaCER group and were not affiliated with any health service agency, and their decision to participate would not affect their ability to receive services or treatments from any organizations. The PaCER method is based on equal peer to peer relationships between the participants and the researchers (patients or community members themselves). It was up to the participants to freely respond or decline the study invitation.

SET Focus Group

We recruited three former ICU patients and one family member who had experienced patient transition from ICU to a hospital ward (three had experience in General Systems ICU (GSICU) while the fourth had experience in Cardiovascular ICU (CVICU)). During the focus group, we asked participants one open-ended question: *"What was it like when you (or your family member) moved from the ICU to a hospital ward?"* After everyone had shared their experiences, we posted the flip chart notes on the wall, asked everyone to look at the flip charts, and identify the themes they thought were most important. The group collectively identified information and communication, and continuity as two major themes that were very important in the transition from ICU to a hospital ward.

Following the focus group, the research team transcribed and analyzed the three sets of data from the SET focus group: digital audio-recording, flip chart notes, and process notes. Based on our analysis and on the comments made by the focus group participants, we revised the interview questions for the COLLECT phase. We wanted to make sure we captured the experiences of both patients and families. We asked probing questions that addressed the important pragmatic topics identified by the focus group without asking leading or biased questions.

We adjusted our questions in an effort to try to focus on the transition experience. However, we realized that, at the start of each interview, we needed to ask a question about why the patient or family member was in the ICU in the first place. We needed this information to put their story into context. Often participants told us a great deal about their health journey, either before the ICU, or after the discharge from the hospital ward to home. We realized that the 'big' story was extremely important to participants and they wanted to tell us this story. The transition experience was just a small component of the bigger story.

We asked family members the following questions:

1) *Can you briefly explain what brought you to the ICU?*
2) *What was it like <u>for you</u> when you found out your family member (the patient) was moving from ICU to the hospital ward?*
    a. *What would have helped you get ready for their move?*
    b. *What helped you get ready for their move? Was there anything else that would have helped you make this move better?*
3) *What was it like <u>for your family member</u> (the patient) when he/she found out they were*

moving to the hospital ward?
   - a. *What would have helped your family member get ready for their move?*
   - b. *What helped your family member get ready for their move? Was there anything else that would have made his/her move better?*
4) *What was it like <u>for you</u> when your family member arrived at the hospital ward?*
   - a. *What would have helped you adjust to the hospital ward?*
   - b. *What helped you adjust to the hospital ward? Was there anything else that would have helped you adjust better?*
5) *What was it like <u>for your family member</u> (the patient) when he/she arrived at the hospital ward?*
   - a. *What would have helped your family member adjust to the hospital ward?*
   - b. *What helped your family member adjust to the hospital ward? Was there anything else that would have helped your family member adjust better?*

We asked patients the following questions:

1) *Can you briefly explain what brought you to* the ICU?
2) *What was it like <u>for you</u> when you found out you were moving were from ICU to the hospital ward?*
   - a. *What would have helped you get ready for their move?*
   - b. *What helped you get ready for their move? Was there anything else that would have helped you make this move better?*
3) *What was it like <u>for your family member</u> when he/she found out you were moving to the hospital ward?*
   - a. *What would have helped your family member get ready for their move?*
   - b. *What helped your family member get ready for their move? Was there anything else that would have made his/her move better?*
4) *What was it like <u>for you</u> when you arrived at the hospital ward?*
   - a. *What would have helped you adjust to the hospital ward?*
   - b. *What helped you adjust to the hospital ward? Was there anything else that would have helped you adjust better?*
5) *What was it like <u>for your family member</u> when he/she arrived at the hospital ward?*
   - a. *What would have helped your family member adjust to the hospital ward?*
   - b. *What helped your family member adjust to the hospital ward? Was there anything else that would have helped your family member adjust better?*

COLLECT Phase

We interviewed 17 participants: 3 patients and 14 family members. In each interview, a PaCER researcher asked the participant the main questions listed above, and after listening to the response carefully, asked additional probing questions to further explore the topic.

Participants found it very challenging to view the transfer experience as a distinct event in their health journey because they found it difficult to separate the transition experience from the context of the other experiences in their journey. Other events in their health journey, either before or after the transition, influenced their perception of the transition experience. The ‘big’ story was very important, and often other segments of the journey were more important to them than the transition from ICU to the ward, and as a result, they told us these stories.

The interviews lasted between 15 and 60 minutes. We recorded each interview and transferred the recordings to our computers. We then transcribed the COLLECT digital audio-recordings of the individual interviews into text documents. Each PaCER transcribed the interviews they had conducted. We each downloaded, using the Internet, the transcription software called ‘Express Scribe Transcription Software’ from the following website to allow us to slow down, and rewind the dialogue during the interview, thus allowing for easier transcription (http://www.nch.com.au/scribe/). Eventually, two of us bought the software at a cost of about $35 Cdn each. This software was of huge value in supporting our transcription work.

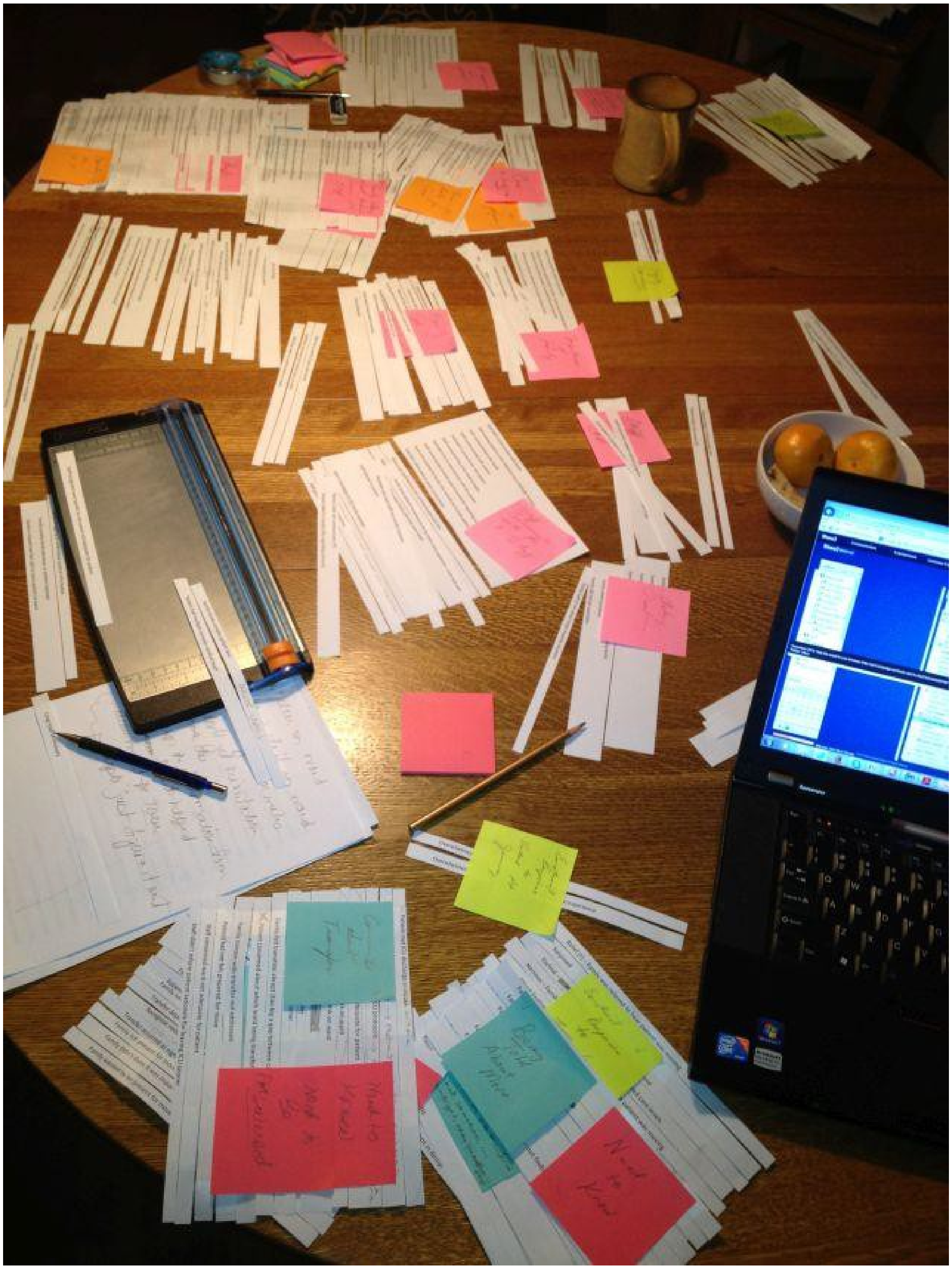
Data Analysis

Individually, we read and re-read the documents to get a general sense of the data. As a team, we assigned codes to segments of texts that corresponded to the themes in the interviews. The codes were not pre-determined, but emerged as we analyzed the data. We coded the data at a very minute level, and created about 400 codes.

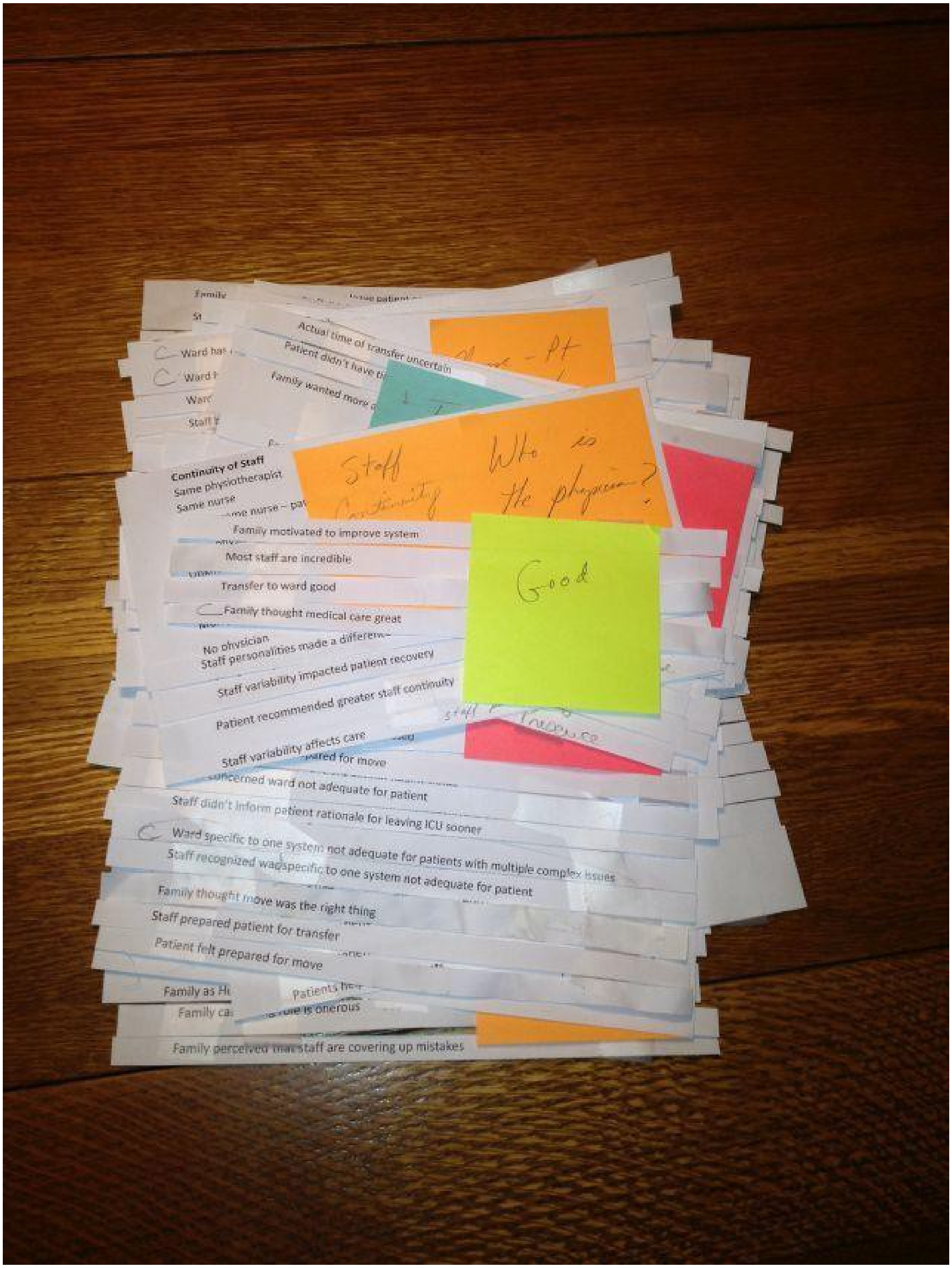
We managed the data using Microsoft Excel. We first entered all of the transcribed interview quotes into a column in an Excel spreadsheet. We then entered the code (or codes) for each piece of transcribed data into additional columns. We later filtered the codes in each column to see all of the quotes that related to the same code.

We grouped the codes together into higher order categories and compared text segments within the same coding category for similarities and differences. By working from the bottom up and by working back and forth between the emerging abstract categories and the data, we organized and grouped the data into increasingly abstract categories that described the experiences of patients and families when the patient moves from ICU to a hospital ward. We did this work together as a team, and often found that we were overwhelmed with the volume of data and the number of codes we created. In the end, we came up with 17 major themes to describe the data.

Picture 1: Two of our PaCER Intern Teammates (Debbie and Donna) hard at work



Picture 2: Our workspace during analysis



Picture 3: Identified themes in one pile

We organized our 17 themes into five main categories. The first three were grouped according to the patient timeline: Before Transfer, The Transfer Process, After Transfer – On the Ward. The fourth and fifth categories, What Families Did and Positive Outcomes, are overarching categories and describe what families actually did in response to a health crisis and the positive outcomes that ensued.

Picture 4: Our PaCER Intern Team (Debbie, Donna and Pete) hard at work

Picture 5: PaCER Interns (Donna and Debbie) and PaCER Mentor (Svetlana) hard at work

The following is a brief summary of each of the 17 themes with a sample of participant quotes that illustrate and support each theme.

BEFORE TRANSFER

Experiencing the ICU

Families perceived the ICU as a highly technical and safe environment with constant one-on-one care provided by easily accessible staff who are concerned professionals, mindful listeners, and skilled communicators. They developed trusting relationships with the staff, although some expressed concerns about how ethical decisions regarding end of life care were made.

> *I was really impressed by the ICU unit. The doors, the glass, it's a brand new unit. It was all new.*
>
> *They were very good to him there. They took really good care. I felt safe with him in there.*
>
> *We knew she was in good hands.*

> *They didn't talk down to us, it was a really wonderful combination of professionalism and concern.*
>
> *You just didn't feel like you were a bother. You feel like these folks did want to connect with you.*
>
> *Leaving him in the ICU was actually easier ... The team, everybody's there, obviously they can deal with emergencies.*
>
> *We didn't get to see her much and I'm not sure why ... We only got in there twice and it wasn't because I wasn't available to go see her. But when we went, they would just say, can you come back in an hour?*
>
> *Although there was 1 nurse for every person in there, it seemed like there were lots of times they were either congregating on one patient or heading off on their break, or doing their charts. I felt there were a lot of times when S was gagging on her airway tube there … "Excuse me, nurse."*
>
> *I was very, very, and very concerned that ... I had made the wrong decision, that I had destroyed her life and future and mine. I felt bullied in ICU to give her, to continue.*

THE TRANSFER PROCESS

Emotional response to being told about the move

When patients and families were told the patient would be moving out of the ICU to the ward, they experienced a range of emotions: relief, happiness, excitement, surprise, optimism, fright, and nervousness. Their emotions were mixed, as they saw the move as a positive step towards recovery and the patient being well enough to leave the hospital, but were concerned about the patient's safety when they moved to a ward with a lower level of care than the ICU.

> *I was really excited because that meant that he was on his way back to getting his health back.*
>
> *I think there was mixed feelings and it was because it was moving from a pretty safe place. I mean it (ICU) is a horrible place to be but not a bad place to be.*
>
> *I think they were excited or pleased I didn't need that level of support, that I was on my way to healing.*
>
> *I said "Mom, the question is, how did you feel when you were supposed to come from the intensive care to the ward?" She said, "Well, I was terrified."*
>
> *It's absolutely wonderful and terrible thing at the same time.*

> *We were thrilled. On one half we were nervous, but on the other half we were thrilled.*
>
> *A big relief going from each one down. Less critical … if there's infection or heart going wonky it's probably going to happen in the first 48 hours. Each passing 24 hours was a benchmark.*
>
> *There is relief but a patient is under such good care in ICU and then when you get moved back to a ward it is a little different.*

Being informed about the timing of the move

Families wanted to be informed of the patient's move in advance, because they wished to accompany the patient during the move and were concerned about returning to the ICU and not being able to find the patient. They recognized that the timing of the move depended on both the availability of a bed on the ward and the need for an ICU bed, and staff were sometimes unable to specify a precise time. Most families would have preferred to accompany the patient in the move, but because they were not always updated on the timing of the move, the patient was often moved at night when the family was not there. As a result, the vulnerable patient was alone in an unfamiliar place without family support, and the family may have returned to the ICU to find the patient missing; a situation that was distressing and less than ideal for both patients and families. In some cases, ICU staff were able to keep complex medical patients in the ICU, even though they met the discharge criteria.

> *But there was no warning given to me. I had no idea that she was going to be moved. I asked for them to let me know. But it was definitely not fun to have that moment where you walk in and she's not there. There was a little bit of a panic.*
>
> *And then all of a sudden, you know I go on a break and I come back, it's like, "Where did S go?" Just came back to find a vacant spot..... It was totally frustrating. OK, where did my wife go? Did she die or did she .... ?*
>
> *But my wife was wondering what was happening. People were walking by us not telling us anything. They just said you were going up there tonight.*
>
> *So much of it was around bed space.... She (patient care manager) would say, "You're the least sick. Depending on what happens, we may have to move you."*
>
> *Well I would have liked to have been there when he was going through that adjustment, because he was delusional and not everything was making sense to him.*
>
> *And I was alone because it was my first day, my first night in a strange place, and I had nobody there that I knew.*

> *So then the transfer was actually made when I was not there. I stayed up that night and I just went to sleep on the couch outside and she was moved when I was not there.*
>
> *We weren't there, and we weren't told it was important for us to be there. We didn't necessarily feel it was important for us to be there. I seem to remember the decision, I think the message was it could be soon, we hope it's soon, but we don't know exactly when, and so I believe the transfer happened late at night.*

Concerns about being moved

Patients are discharged from the ICU to the ward when they meet the ICU discharge criteria, and some families would like a more complete explanation of those criteria. Patients and families were anxious about being discharged and moving to a ward because: (1) they were concerned the patient was not well enough yet and was being discharged too soon, (2) although the patient met the ICU discharge criteria, they were worried the ward would not meet the patient's needs, particularly in cases where the patient had complex multiple issues, (3) they were concerned with reduced level of care on the ward, and (4) they were concerned about an increased risk of infection on the ward.

> *I just really wondered if it was too soon to release her from intensive care.*
>
> *I don't think they were really equipped for someone with a brain injury. And he just kept getting up and leaving and he got out five times in one day.*
>
> *You may as well check out of the moon and go to earth ... He met all those criteria to be released. So they released him. Then 3 to 5 days later, he went septic, coded again, went back into ICU.*
>
> *She's got one-on-one care and she's going onto a ward with an LPN checking on her. So I know that has always been a worry for her.*
>
> *There was a gaping hole in his neck and he was worried that it was going to be infected.*
>
> *There was one male nurse, J, and he was really good. Like, he made my stay there great. He helped prepare me to do the transition and he was really, really good.*
>
> *So we were just waiting to see which unit would take her. Because they had some other beds in ICU, there's no rush, let's take our time, do the tests and stuff. And then let us know there's an opening. You'll just stay with us.*
>
> *They said it's a special unit for ENT, this is a special unit and everything's ready, expert in the care, especially for this type of operation. They said, "You will be fine." Nurse*

> *explained me, "He's ready for this", the whole team, the ICU team, all this unit team, the ward he was transferred, they all came in the morning and were discussing.*

Transfer of information

At the time of discharge, patients and families assumed the medical information was transferred, but in hindsight, they questioned whether all the information was transferred, read and comprehended by the ward staff, particularly in complex cases where the volume of information was extensive. Families felt it was important ward staff should be aware that the incoming patient was delusional.

> *I think it does. Though, in her case, there's so much that they have to go through it and it takes time.*
>
> *It is a lack of transfer. Someone has seen that patient, but their initial prognosis or diagnosis or whatever does not seem to be transferred to the next doctor and then there is another doctor.*
>
> *And when we did finally get to go to my mom, she was absolutely nuts. She was acting like a crazy person. And so what they didn't know and what made it unfortunate, is they thought she had dementia ... Because of her age, they assumed this is what she was like.*
>
> *I think so, because they didn't ask us anything, they didn't ask us.*
>
> *You always wonder how much information gets transferred from one doctor to another.*
>
> *The assumption was, yes, but at each successive step we started to wonder more about that.*
> *I was happy with all the information they gave ... More than one hour they took to transfer and like, according to them, ICU nurse gave report to them.*

AFTER TRANSFER – ON THE WARD

Feeling disoriented

When patients and families arrive on the ward, they do not know the physical layout, staff, or 'rules' on the ward. The majority did not receive an orientation and were left to figure out this new environment on their own. Their disorientation became a factor that contributed to their feelings of vulnerability. Those patients and families who received an orientation or who had previous experience staying on a hospital ward or who had received information from friends with ward experience were less disoriented.

> *The physiotherapists are different, the doctors, the nurses, everybody is different.*

> *I didn't know what all the rules or the regulations for the ward were.*
>
> *But it's not familiar anymore, you're not exactly sure what the rules are, what they aren't. It looks, dare I say, less spiffy, less high tech ... You're in a ward where things are older, less organized looking, fewer staff.*
>
> *And so the staff over there, they didn't say anything, they didn't introduce themselves, "What's his name, I am his nurse and this is what we are doing." Nothing.*
>
> *On unit 58 they gave me a little tour, like where his room was, the community room, the lunchroom ... and explained what would be going on, showed me the board where his therapies were, where he'd be at what time.*
>
> *We more or less we knew what it would be like on the ward because we were already there and she almost spent a month on the ward in September, we knew kind of the procedure and what will be happening.*

Feeling vulnerable

Many patients on the ward felt vulnerable, were still delusional, and did not want to be alone without the support of their family. Patients who had never been in a hospital before struggled, because they did not know how to be a 'good patient' and were often impatient to go home. Some families were shocked at the level of care, did not trust the staff because they had witnessed medical mistakes, unsafe patient practices, unhygienic conditions, and felt they had to be there to oversee the patient's care.

> *When he went into the hospital, he wanted me there all the time. At first. He didn't like it when I left.*
>
> *He was afraid, yeah. Sometimes he thinks that, "I can't breathe now, I can't breathe now." So we have to hold his hand.*
>
> *When I found her on the floor, I checked her out, I got her up, and I got her back in the bed. I called the nurse and I said, "What happened?" "I just left her a few seconds." "No you didn't. It has been at least 2 minutes since I found her, checked her, got her back in the bed and I didn't see her walking out of her room." Her head probably missed the sink by an inch on the way down.*
>
> *We had one nurse come in ... she has purple hair ... then she said "Where did they take the veins out of your legs?" We didn't have a bypass, we had a tumor that just got taken out. "Oh, oh. I guess I should read the charts." OK, so we're trusting this person with medications and everything else..... It gives you no confidence.*

> *This is the first time I was ever in the hospital I mean it was all overwhelming. I was an emotional train wreck. Right from there it spiralled downhill all the way.*
>
> *Every time I would go see him, maybe 2 or 3 times a week, he would say it is really good here ... He was quite content there it seems. Once he was there on the ward he was quite content.*

Adjusting to the ward

Patients and families had to adjust to the hospital ward, which for the majority, was another unfamiliar place and very different from the ICU. We categorized their adjustment into five groups: (1) Physical environment - the physical environment of the ward is different than ICU and unfamiliar, often noisy and crowded. (2) Nurse/patient ratio - Patients and families recognized that nurses care for more patients on the ward and were very busy, which affected the level of care they could provide. As a result, families often experienced difficulty locating nurses and they sometimes hesitated to bother busy nurses. (3) Variability in care - Patients and families felt their care was better when the same staff provided care in a caring manner. They perceived that variability between staff, both in terms of medical skills and compassion, and differences in individual staff personalities affected their care and impacted their recovery. (4) Access to physicians - Patients and families felt it was important to have access to physicians on the ward, and reported they often did not know who, how, when and where to find the ward doctor. (5) Needed to know about plan of care - Patients and families needed to be informed and updated regarding the patient's plan of care and steps toward recovery. As the patient's health improved and they became more cognizant, they wanted to be included in these discussions.

> *I felt like I was in a locker room and it was awful for me.*
>
> *It was brighter and noisier and much more confusing than what we had expected.*
>
> *I noticed right away there's less nurses and it's not as stable. Not as secure.*
>
> *My sense was always that the nurses were multi-tasking, even as they spoke with you. Were trying to do their work, 50 million other things that they needed to do.*
>
> *10 different nurses, 10 different personalities, 10 different ways of doing things, 10 different priorities.*
>
> *On the ward, we never knew when somebody (physician) was going to come around, we never knew.*
>
> *We actually never did know who was looking after Dad on the neuro Unit. We never saw them.*

> *D was transferred to a physician who was not present for 6 weeks. When she did show up, she was terribly disruptive.*
>
> *Our doctors were visiting every morning ... Doctors were doing their rounds properly. Who take out the cancer, and other doctor, three doctors. So they were making rounds.*
>
> *He was with R and I always saw him there. And it was really nice that we always saw the same doctor.*

WHAT FAMILIES DID

Reducing vulnerability

Families helped reduce patient vulnerability by providing social interaction and support for the patient. Both patients and family expressed concerns for those patients who did not have family members at their bedside.

> *He would say I want you to come back. I would say, "Why?" and he would say, "Cause I don't see anybody when you are not here. I am alone."*
>
> *I told her to phone me every night. And we'd get her into bed and we'd talk her through that. And I'd say, "There's no one here, it's just you in a bed, and I'll just talk to you until you fall asleep." And she'd calm down and she'd go to bed.*
>
> *They got a couch ... I took off my shoes and talked a little bit. We kind of cuddled up and went to sleep. It was dark and quiet. I think it was dark at night, but this was a sense of quiet relief.*
>
> *I don't know how people do it if they don't have that support. It would be really hard if you're 75 and you're coming out of ICU and you don't have anybody there, to hold your hand and say "Yeah, you're doing good. What do you need? Do you need to be rolled over? Do you need another pillow?"*
>
> *One of my huge distresses in the hospital was there were people who had no one to advocate for them and to help them. And I was so worried for them because I could see what was happening with me and no one was helping.*

Providing care

Families wanted to help with care, but they didn't always know how or what to do, and struggled with understanding their role on the care team. They sometimes took the initiative in providing basic care and housekeeping services, and assisting with medical care and rehabilitation. They reported that the family's caregiving role can be an onerous task. Families with a healthcare background had to strike a delicate balance between the caregiving role and their professional expertise.

> *(We) were having to perform his mouth care because he had bit his tongue. Dentists were involved and he had an ulcer under his tongue.*
>
> *In the step-down unit, for the whole time I was there, I was the one to go get her a warm blanket, I was the one to get her ice chips, going to get juice, anything like that.*
>
> *We just thought, oh my God, I'm going to have to sit there all freaking day, because who knows what's going to happen, because she has good moments and bad.*
>
> *Can you ask housekeeping to take out all the garbage? They said, "Oh yeah, she is coming, she will do it." I wait, wait, wait and nobody do anything. So I was the one who was taking all the garbage.*
>
> *We tried everything in the hospital to get an Italian speaking social worker, somebody consistent (to)be me basically. I had to give up my business for 13 months. Raising my children and everything. It was brutal.*
>
> *We just thought, oh my God, I'm going to have to sit there all freaking day, because who knows what's going to happen, because she has good moments and bad.*
>
> *Fatigue was a very significant issue and in fact I had some periods where I had three near close calls driving when I had micro sleeps. I woke up to the rumble strips and moving toward the ditch.*
>
> *I kept saying that I think he has thrush......... They kept saying, "No he does not have thrush." His mouth was getting more and more coated. We were trying to do different things and when he finally was moved to Hinton, the first thing they did was say, "Oh my goodness, he has thrush!*

Figuring it out

Families observed the patient closely and frequently, and came to know the patient best. Often, family members (or patients themselves) identified medical concerns and possible solutions, which they brought to the staff's attention. Sometimes the staff listened and acted on their concerns, but often they did not.

> *One of the things we were always questioning from the very beginning, was did the Imuran cause these initial symptoms?.... Within 2 hours put back on the Imuran, (she) developed a pretty significant rash, her fever was raising, and they determined she had developed pancreatitis.... But in my mind and my wife's mind was pretty obvious that the Imuran was causing it.*

> *He had constipation for, from the surgery, I think six days. And I asked, "Nurse, ... can you please check?" The nurse said, "Okay, I will do." Didn't do anything. Next day again I remind, "Did you ask the doctor, please for constipation?" Nothing. Third day. Still same answer ... They never came back and asked ... So what I did? From home, I brought suppository and I give suppository to my husband. And I didn't tell them I did that.*
>
> *I remember us saying, you know, she has a lot of allergies. And could this not be a side effect of one of the drugs? ... And they kind of said, "Oh, well, maybe ... Maybe that's what's going on. I'll mention that to the doctor." It was so casual. When inside I'm thinking, I just want to slap you, because could you just get on this right now!*
>
> *When I talked to the doctor I said, "So how severe is this concussion?" "Oh, she has not had a concussion." Even at that point they were minimizing it.*
>
> *I had to be there to say, "That 37.5 fever, he's going septic."*
>
> *She has bad shoulders, so she couldn't reach the call button. In fact, I had to take her a drumstick, because she wasn't strong enough to push the call button ... She could use a drumstick with two hands to push the call button.*
>
> *They were so busy they could not take the time to come in and figure things out, I guess ... They would forget to put his hearing aids in and then they would say, "Well he was unresponsive, and didn't communicate with us." We would go in and put his hearing aids in and he would look and say, "Oh there are people here!" We would say, "There is a big sign above his bed saying to please put his hearing aids in," but they just seemed* to *really not pay attention to those little things that kind of make a big difference in his ability to respond and communicate.*
>
> *But the spelling of her name on that (IV pole) was wrong. And ... she had the same last name as someone else. So, for the spelling in the name to be incorrect. I wasn't sure if it got switched with another patient who has the same last name ... When I went up to the day nurse, she said "Oh no, it's fine". With no explanation, no anything.*

Advocating

When family members felt the patient's medical issues were not being adequately addressed, they advocated for the vulnerable patient regarding the plan of care. They perceived their advocacy was particularly important for patients with a complex medical history and was valuable because it was patient-focused, unlike the hospital which is unit-focused. They expressed concern for those patients who did not have a family member to advocate for them, or for family members who had barriers that prevented them from advocating. They suggested that having access to a patient-focused navigator/advocate would be helpful for all patients and families throughout their healthcare journey.

> *It made me really question what my Mom's treatment would have been if I wasn't there to stand up and ask. Because my Mom was obviously fully incapacitated, she just had open-heart surgery.*
>
> *I raised a stink and no, I am not a shy person ... I am not a bull in the china shop, but I am also not shy ... When I am advocating for something that is important, like in this case, my wife, I will not take "no" for an answer. I don't get grumpy, I don't get angry, I don't stomp my feet or do things like that. But you know I will, I can be very firm and very matter of fact. That is exactly what I had to do over and over and over again.*
>
> *It was me. It was totally me. I put my life on hold for 3 months, 8 hours a day at the hospital. And I truly do believe that is one of the reasons he's still here 7 years later.*
>
> *That idea that the patient is in the centre, and the family is there to advocate there, and the staff is there helping to get well – it takes a whole village to heal a critically ill person.*
>
> *I think there should be a person who is patient-based not unit-based, and they should follow the patient around the hospital. There would have been a familiar person to call.*

Interacting with staff

Patients and families wanted to engage with staff in a meaningful and caring two-way conversation. They: (1) needed to know and be informed consistently and honestly, (2) needed to be heard by staff, (3) needed to ask questions, but had to overcome barriers to asking, (4) needed to be answered, (5) needed to be asked, and (6) desired a two-way conversation that made them feel cared for. They reported that communication could be difficult in situations where the primary language of the either the patient, family member or staff was not English.

> *The patients are much more aware than some people give them credit for. Very few people made that mistake with B because she would write on her clipboard, she would write questions and stick the clipboard in your face and you had better read it and answer her question.*
>
> *Then the intensivist said, "Is he trying to communicate with you." She was quite surprised because she didn't think he was able to communicate with anyone at all, because I guess they were not taking the time to communicate with him.*
>
> *You don't really know what to ask. Let me qualify that. I think I didn't know, in the sense, what I was allowed to ask.*

> *And I said, "okay, what do we really need to know?" ... You want to prioritize ... and that's ridiculous actually to think about that. How do I know what's important?*
>
> *They would constantly tell me lies upon lies and cover-up. I don't know why. I was asking for straight answers. When was the doctor going to be here? Why isn't there a doctor always on duty on this ward?*
>
> *I think just they need to be very open because the families are the ones that have been there from point A to point B. If staff are not able to communicate everything between each other than they need to ask the family.*

Keeping the story

Because family members were involved throughout the patient's healthcare experience, they tried to piece together the whole story of the patient journey from ICU to home as best they could. They felt keeping the story was an important task because they perceived the healthcare system consists of narrowly focused specialties with a lack of continuity between components of care. However, family members often had unexplained gaps in the story, which prevented them from getting closure on their health experience. Patients found value in reviewing their family journal to make sense of their healthcare journey.

> *When my wife was released, of course they had given me a discharge summary of everything that had happened when she was there. At that point I went through and wrote down a bunch of things in my mind that had happened. It is kind of, in my mind a biased report. I think there were things that were missed and diagnosed with my wife that were not mentioned like the Imuran. She is no longer on the Imuran.*
>
> *It (the journal) was helpful for us. A lot of things were happening in that short period of time that our brains were becoming jumbled ... We could go back and say this is when this happened or we already talked about this.*
>
> *I have this form that I keep updating and it has a list of her allergies, because she has extremely dangerous allergies ... So I have a list of all her allergies, I have a list of hospital stays, I have a list of some of the doctors, not all of them, I have a list of procedures, where they were done ... So we arrive with hands-on things that we are concerned about that we don't want them to miss.*
>
> *Once he was able to write again, he was continuing with that (journal). He will actually go back and refer to that, because he does not remember anything until he went back to Hinton. On the ward he does not remember anything about ICU or the transition unit.*

POSITIVE OUTCOMES

Feeling treated as a person

Patients and families felt that if staff interacted with them in a caring, compassionate, respectful manner and incorporated small gestures of kindness, they were being treated as a person, not just a patient/family member. Those who received compassionate care felt this enhanced their recovery. Some patients and families perceived that sometimes the nurse's role in care seemed to be 'medical' only.

> *Never even smile at you, you know, you don't exist ... They just think that we don't exist. We are not there ... Because we are brown, they didn't care ... Don't say hi or nothing, at least you can smile to them. Some gesture of kindness.*
>
> *I happened to walk in to one nurse saying to him, "Well you can just pee in your pants ... I don't have time to help him with the urinal."*
>
> *I saw a man who was visiting the man across from us and the door's wide open, and he glances in, and there's my naked mother on the pot ... Would you do that to your own mother? No, you wouldn't. Why do it to my mother?*
>
> *He became to know the girls looking after him. They would tease him, they would talk to him and they would listen to him.*
>
> *He said that the people that came around were always nice. They asked how he was doing. They were able to chat and he enjoyed that. It made him feel more welcomed and more relaxed when he was able to chat with the nurses and the people making rounds.*
>
> *I just wanted to say again, that the night shift nurse was really incredible. I felt very comfortable with her. She was very sensitive towards any of my questions or anything that my Mom needed, Adjusting pain medications, she was great.*

Being engaged with the team

Families wanted to help with the patient's care and needed to be invited to become part of the team because they usually did not know what their role was and how they could help.

> *I am good in creating and involving relationships. That is part of the advocacy process. I built relationships with her hospitalist and a few key nurses.*
>
> *So the night nurse ... I don't know how we would have done it without her. Because, between the two of us, between her and I, we were really able to narrow down the pain meds and figure of what worked for my Mom and what didn't.*

> *They kind of made us a part of it which was really nice. We sat down and it was J and his doctor and all his therapists and my parents were there and his dad was there and they involved us in it. In what the plan was.*
>
> *Part of the education and support of families means giving them a role. Helping them, not just saying, "Well, you just let us know if anything changes." Like what? I might notice, but can you give me some signposts here? Concrete jobs, to feel useful.*
>
> *You could feel a lot of anger and frustration in that they (families) did not know what they could do to help. We saw 10 families. And those families you could often see the frustration on their faces because they often did not know. There were a few incidences and we did not know the context, but you could see the anger and hear their voices. I saw a lot of frustration.*

Feeling confident and safe

When staff listened and acted on patient and/or family-identified concerns, their actions helped the family develop trust and confidence that the patient was safe and receiving the appropriate medical care.

> *She had adequate pain control and she started respond. Physically, her body started to wake up. She started to respond in occupational therapy. Very shortly thereafter, we were able to get her up and walk with support. Only because she got the pain control to be able to function.*
>
> *We had a sense of trust that there were good people back there ... It ended up she got stronger and stronger, more and more physio. And again we developed a sense of trust within there.*
>
> *I don't know how we would have done it without her. Because, between the two of us, between her(nurse) and I, we were really able to narrow down the pain meds and figure of what worked for my Mom and what didn't.*
>
> *Her catheter partly pulled out. And it was hurting her a lot ... One nurse said "Well, there's nothing we can do about that." And S is writhing around in pain for however long, and then the new nurse comes in ... Then the nurse said "What do you mean we can't? … Of course, we can do something about it. Just sit back and relax." Just reinsert it or whatever.*

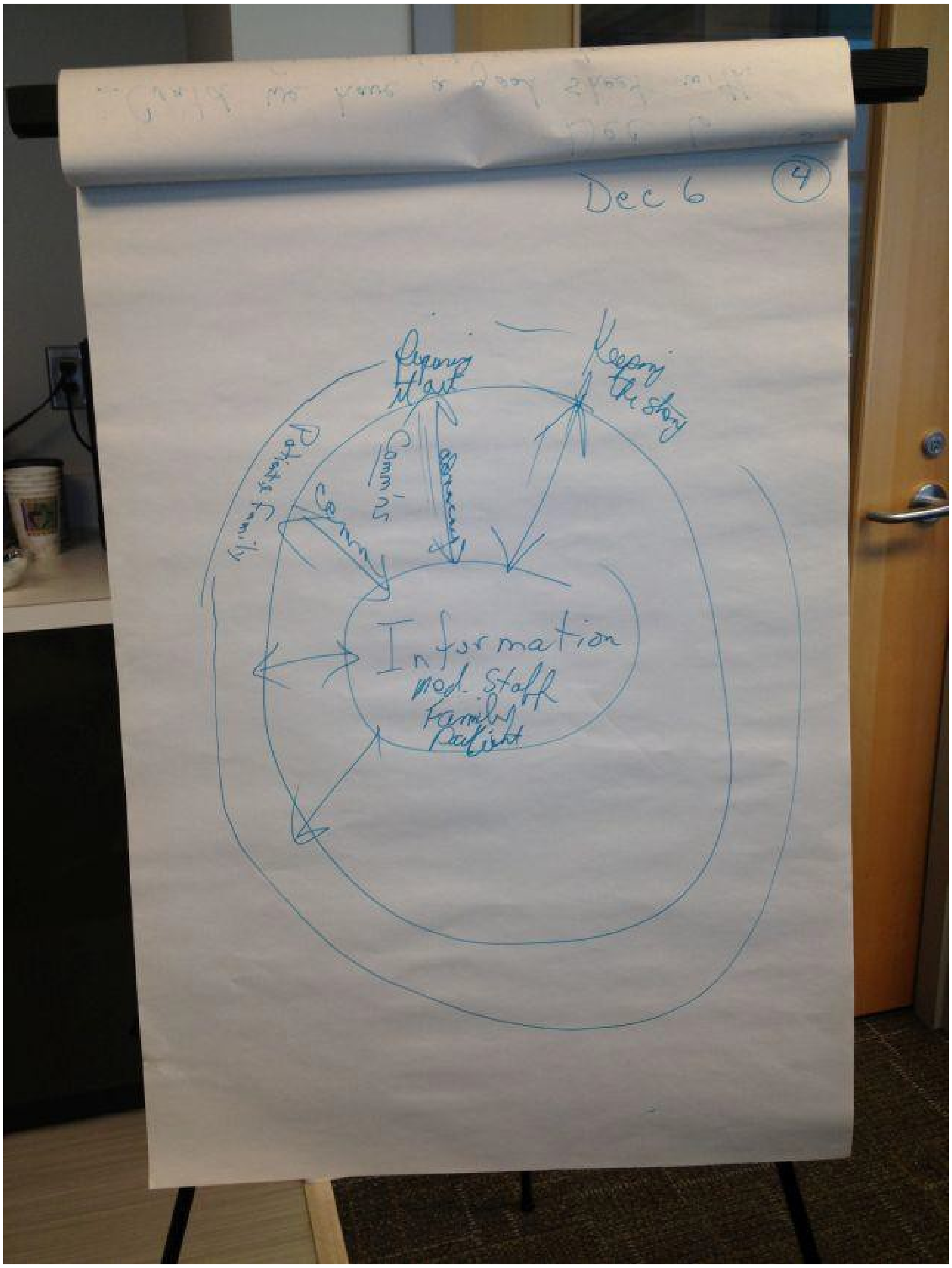
REFLECT Focus Group

We presented the 17 main themes from our analysis of the COLLECT data to the original 4 SET focus group participants to seek their reflections. We displayed 17 posters on the wall. Each poster had a main theme, with a brief description and supporting quotes for the theme.

Picture 6: REFLECT Focus Group participants, and researchers, at work

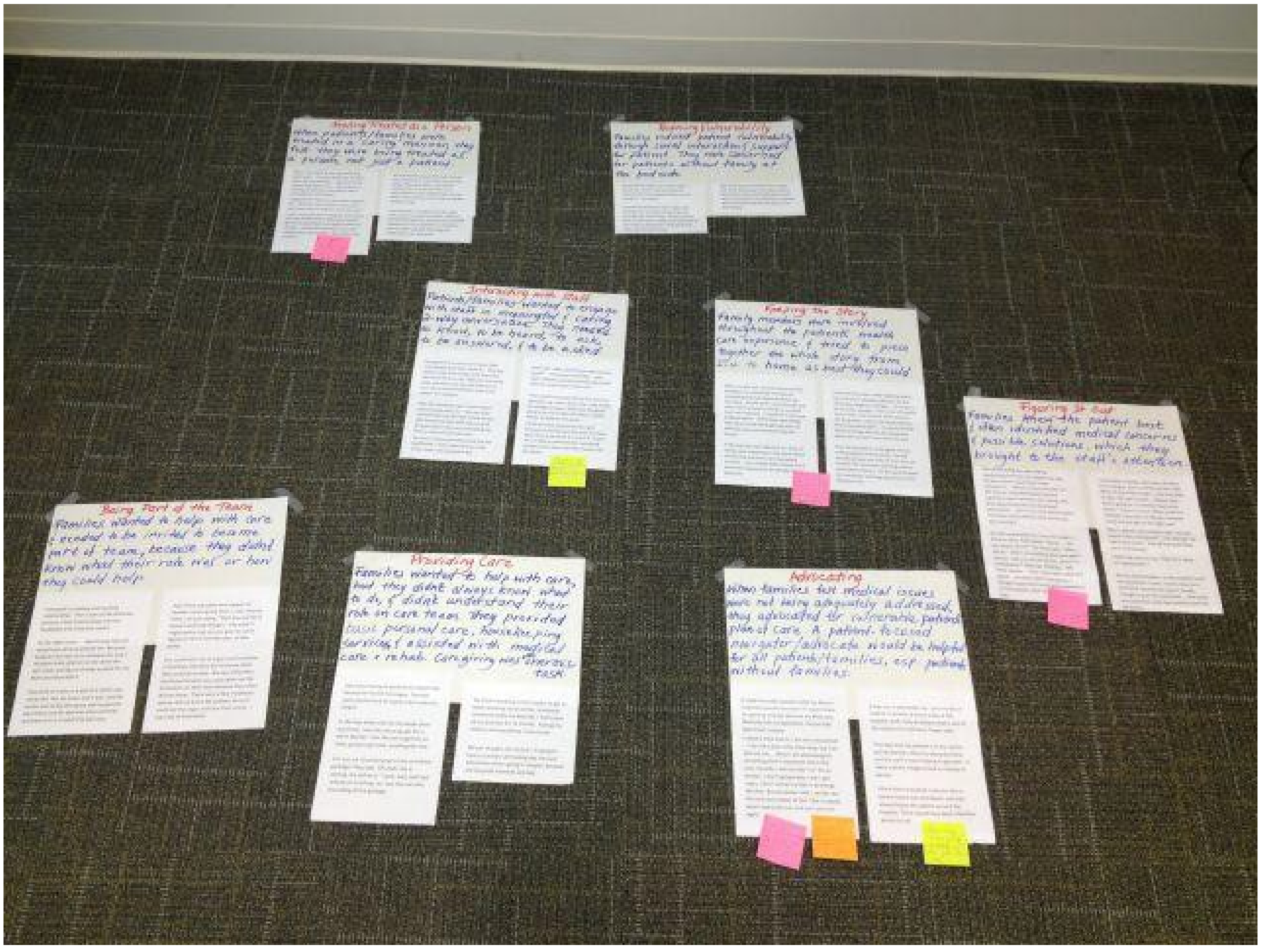
In hindsight, we realize this was too much information to show the focus group participants. It was probably overwhelming for them, and by being fixed on the wall, the information already seemed finalized. We wanted to discuss with them whether these findings resonated with their experiences and represented collective truths that recognized the diversity of the group, but it was too much information for them to process. We had some challenges getting the group to engage in this process. Perhaps if we had presented less information, or presented the information on a large table to show the work was not yet complete, it would have been easier to get the participants to engage.

However, part way through the focus group, one participant asked what we were going to do with the information. We replied that we wanted to create a model of how all the categories fit together. She came up with the idea that information and communication should be at the centre of the model, and drew a model on the flip chart.



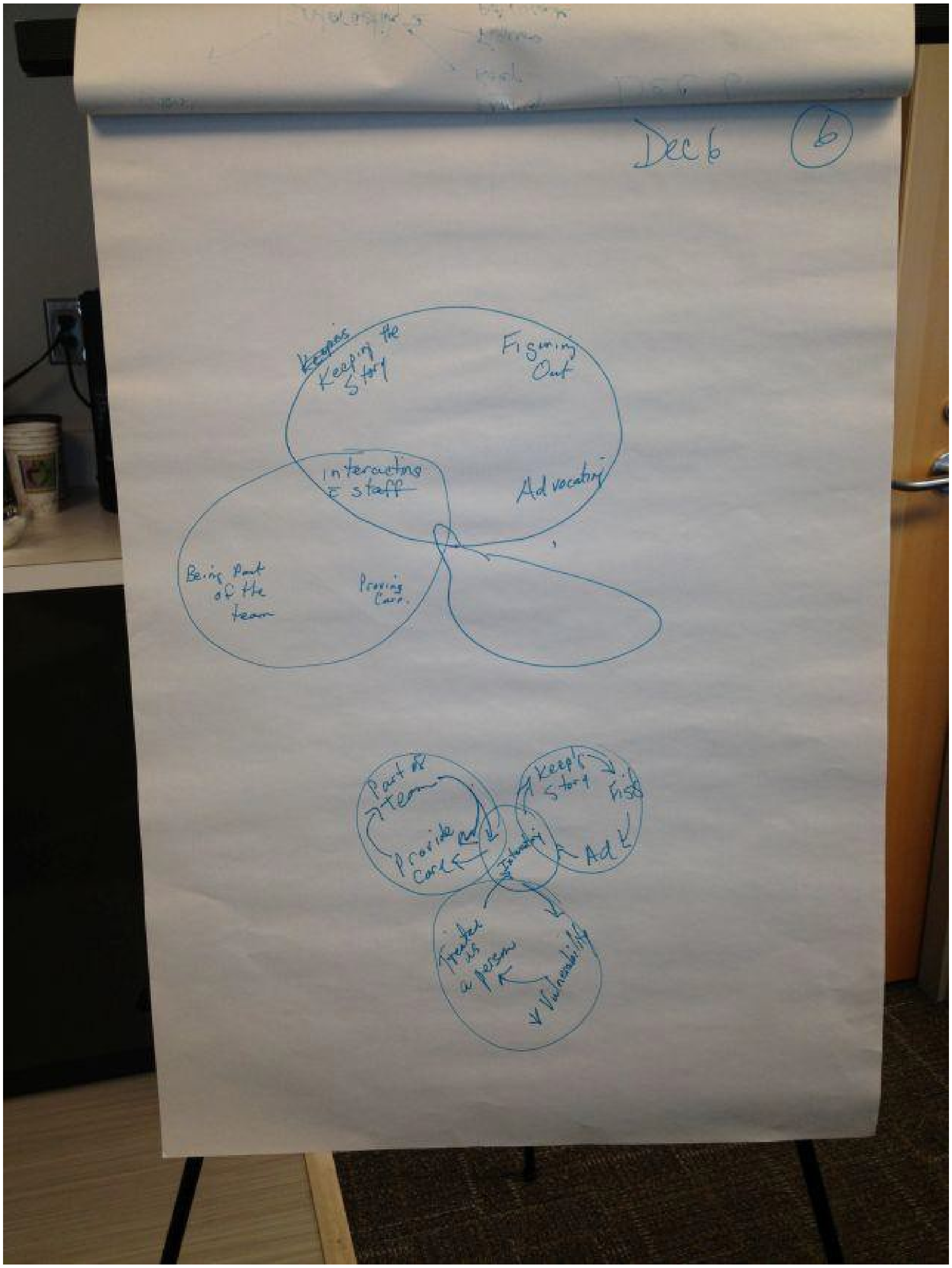
Picture 7: First model showing communications and information, drawn by participant

This started a discussion about how everything fit together. We took some of the posters off the wall and laid them on the floor, so they could be moved around.



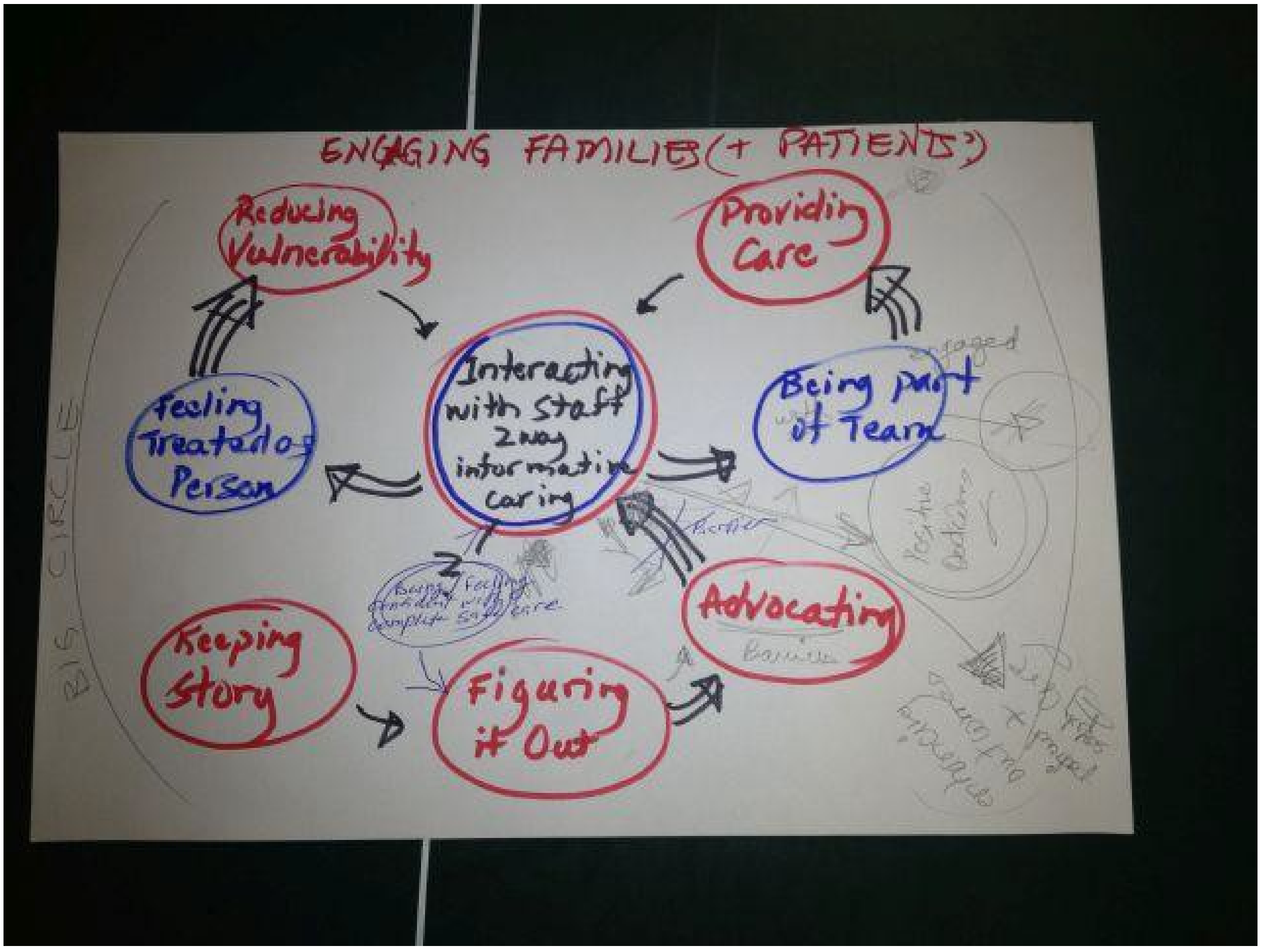
Picture 8: Some themes from the wall, now on the floor

We discussed and came up with a preliminary model that explained the overarching categories in the data.



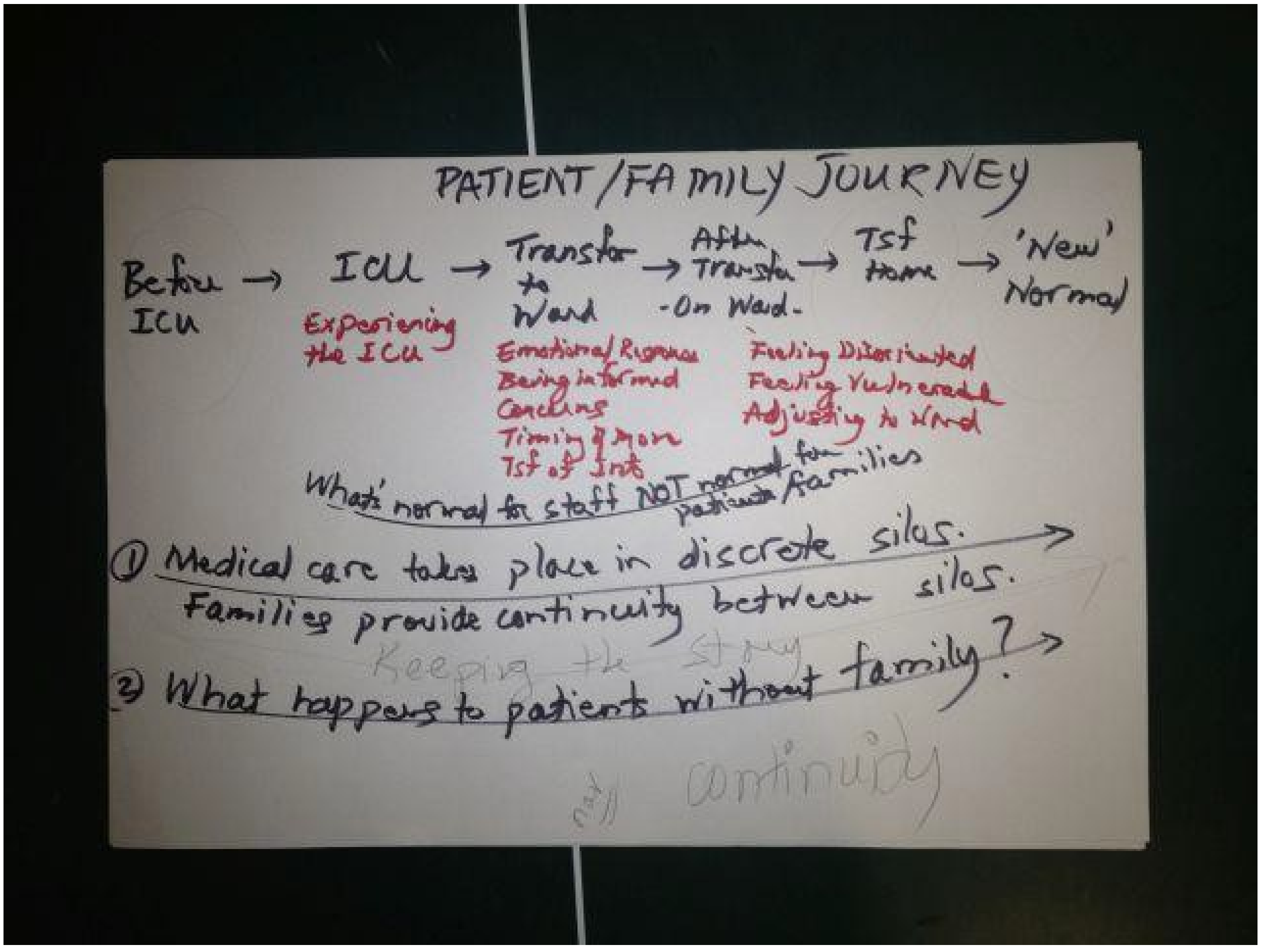
Picture 9: Preliminary model to explain the overarching categories

Later, we worked with our PaCER mentors to further refine this model:



Picture 10: More refined model to explain the overarching categories

We created a second diagram to show the Patient and Family Member Journey from Before ICU, Being in ICU, Being Transferred to a Hospital Ward and eventually Transferred Home and adjusting to the ‘New Normal’. Each of the themes identified were mapped against this timeline, with some being at a specific point in the timeline, and others being across much of the journey.



Picture 11: Diagram showing Patient/Family Journey

Strengths

The strengths of our study are related to the PaCER method (which utilizes a phenomenological framework and is conducted by patients or family members), the engagement of participants in the SET and REFLECT focus groups, the richness of data collected during our COLLECT interviews, and our method of analysis.

Although our interviews were semi-structured, we exercised a great deal of flexibility during the interviews, which allowed people to tell their stories without being constrained to pre-determined questions. This enabled us to more fully capture their experiences. Because we are patients and/or family members of patients ourselves, the power differential between the researchers and the participants was reduced, which may have given people the trust to more fully disclose their stories/experiences to us than with a traditional health researcher.

In the SET focus group, participants outlined what they felt the most important challenges were, and in the REFLECT group we re-visited those challenges, which were embedded in our findings, and we started to create a model to explain how the themes were related.

Last, we analyzed our data as a team, which ensured we were in agreement on the data codes, and the codes resonated with each member of the team. Each of our team members brought their unique skills 'to the table' and by working closely together, we feel our resulting product is better than if it had been done individually. Because our codes were not pre-determined, the themes emerged from the data, not from categories based on the literature or previous findings. It is interesting to note that some of our findings have not been previously reported in the literature.

As a team, we recognized the importance of making the SET and REFLECT Focus Groups comfortable for our participants. We divided up responsibilities in buying and bringing drinks and food, finding that few people drank soft drinks, preferring coffee, tea or water. We learned that wrap sandwiches (that don't get soggy), a vegetable tray, fruit and cookies were well-received by participants and us when it came time to eat. A couple of our team members brought their tea and coffee-making equipment from their homes to cut down costs. We also arranged to borrow the flipchart stand, paper, markers and plastic tack from our PaCER Mentors as the meeting room did not have this equipment ready for us to use.

Cautions

Our findings reflect the experiences of a small group of patients and families, and may not be generalized to a wider population. For example, we did not recruit any non-English speaking or Aboriginal participants. It is unclear to us the extent to which our patient and family member participants represent a good cross-section of the types of illnesses experienced by people in ICU. People who agree to participate in studies such as this may represent a group of motivated patients and families who wish to be more engaged in healthcare, and it is possible that many people who did not participate do not share this same interest.

This study focused on adult experiences in ICUs and did not include neonatal or pediatric ICUs. This population could be included in a future study.

We learned that recruitment of project participants is a tough task that should not be assumed to happen quickly or taken lightly. It is not clear to us if there are any magic answers on how best to do successful recruitment. Many of our participants came through personal contacts – yet, we wonder if this is the best way to recruit participants. The value of collecting lessons learned (positive and not-so-positive) on recruitment experiences may be of great value to future teams.

We found it very difficult to get people to commit to a focus group (SET, REFLECT) of 5 hours. Most of our participants remembered their ICU experience as if it was yesterday, and really want to be part of making ICU better for the future. However, people are simply very busy and a 5 hour time commitment is significant. In future projects, this 5 hour time commitment should ideally be re-evaluated to see if there are less time consuming, more creative, attractive options to encourage better focus group participation.

We enjoyed hosting our interviews, finding it a real privilege to hear the experiences of patients and family members. The difficult part after each interview was the transcription, which was very time-consuming. Even using the transcription software to slow the playback speed, it took us about 3 to 6 hours to transcribe a 1 hour interview. After completing the transcriptions we were exhausted, even before we embarked on doing our analysis.

We appreciate the internship is to provide an atmosphere of learning, and we fully support this. However, we did ask the Critical Care SCN Assistant Scientific Director how they handle audio-tape transcriptions. She indicated they always build into each project budget funds to support audio-tapes transcriptions being done by an outside company. We suggest PaCER consider this in the future to offload PaCERs from this arduous task.

We decided to put all our interview transcriptions into an Excel spreadsheet and assign themes and sub-themes for each quotation. We did this as a team as it allowed us to become familiar with the data, assign themes and discuss the analysis as a team. The use of an Excel spreadsheet (with filtering) did work, although we question if it is the best tool to analyze this qualitative data. We understand there is a software product called NVivo which helps do this type of qualitative data analysis. We suggest that this type of tool be considered by PaCER going forward to help with data analysis.

Impact Potential

We are writing a scientific report to share our findings with Dr. Tom Stelfox (Scientific Director for the Critical Care Strategic Clinical Network (CCSCN)) and his team. Our results will be amalgamated with their medical study about the transition from ICU to the hospital ward titled "Reengineering Patient Discharge from Intensive Care" (Ethics ID REB13-M0D1). Since our results will be going directly to the CCSCN, the potential for impact could be very significant. Although we have identified some very broad topics, participants have also made some specific recommendations to improve the transition that might be relatively easy and inexpensive to implement.

Publications and Presentations

In addition to writing a scientific report to share with the CCSCN, we will be working with the PaCER team and the CCSCN to target a journal for publication in 2015. After a journal has been identified, we will then re-write a portion of our findings to submit for publication. We have also discussed creating an audio-visual presentation of our findings that would be suitable for the Critical Care Patient Family Centred Care Committee and front line staff. This presentation might be a Podcast, PowerPoint presentation, or a Prezi presentation with video clips from our participants to illustrate the findings and tell their stories. We think it is very important to create a presentation that will convey the powerful messages embedded in our findings without requiring people to read a very long scientific report.

PERSONAL JOURNEYS

Debbie Boulton

In my previous 'nine lives', I have worked as a geophysicist in the oil industry and as a stay-at-home mom raising two wonderful sons. When my older son was diagnosed with a severe autoimmune disease 7 years ago, I returned to the University of Calgary to study Health Sciences through the lens of the social sciences. During my studies, I came to recognize the importance of the patient and family voice in healthcare and strongly believe that patients/families are under-utilized resources in our health system. When I became aware of the PaCER program, I instantly aligned with both the methodology and philosophy of the program. I enjoy engaging with patients and families, hearing their stories, and believe this type of research can both improve health outcomes and reduce healthcare costs.

Although ICU is not my main area of interest, as I started to work on this internship project, I became more and more engaged and fascinated in this topic. During the focus groups and interviews, I heard powerful stories from patients and families, and felt a tremendous responsibility to honour their voices and convey their stories in a way that will lead to improved patient and family experiences. I believe one of the main strengths of the PaCER method is the capacity to capture the collective voice, but still honour individual stories. We chose to analyze our data thematically, which seemed to best fit our particular data set. However, another group of PaCER interns analyzed their data using a narrative approach, which I found very interesting, and I would consider using this analysis method in subsequent projects, if applicable.

I found great value in working with a PaCER team throughout the project, especially when analyzing the data. I believe that integrating and incorporating the ideas of people with different backgrounds and skills leads to a better product. We struggled with and continue to struggle with the best format of conveying our results, as we know that busy healthcare workers will not have time to read a lengthy report.

In terms of personal growth, I found critically listening to my recorded interviews very instructive. Sometimes, instead of jumping in with another probing question, I would do better to be more patient and let the interviewee continue with their story. I also feel I need more practice, and perhaps more training, to become a better facilitator for a focus group. In both interviews and focus groups, I need to work at putting people at ease, as this is essential to gaining their trust and enabling them to tell their story.

Last, the PaCER internship project has confirmed to me the importance of the patient and family voice. We are an under-utilized resource in the healthcare system and our voice is an essential component to improving the system.

Donna Oswell

My PaCER journey has been an evolution in thought, experience and belief. A friend met me for coffee to tell me about this “exciting research course called PaCER”. Forty- five minutes and a latte later, my interest was piqued. I have been involved in the area of patient and family centred care for over ten years and the PaCER program seemed to dovetail with this framework of care.

I attended the first class and was amazed to see such a variety of people interested in taking this course; people dealing with their own health issues, along with having different levels of education, professions, work and life experiences. It became even more apparent to me the importance of engaging patients, families and the community in making healthcare changes. Initially, I was skeptical of the impact this type of research would have in the healthcare community. Could PaCER research findings actually influence health professionals to make changes to our healthcare system?

Throughout our program we had the opportunity to practice many research skills. Even though I have taken research courses at university, I never had the opportunity to participate in some of the research methods discussed such as observation, interviewing, focus groups and narrative research. It was more challenging to do than I thought!

My research partners and I had the opportunity to assist with some focus groups as PaCER interns. PaCER researchers consist of patients, families and community members who have experienced the healthcare system. It has been noted that participants often feel more comfortable talking about their health experience with PaCERs than healthcare researchers perhaps because there is less of a power differential and more of a peer to peer relationship with PaCERs.

I certainly have experienced the healthcare system from the perspective of a parent, having a son with Down syndrome and who also was treated for leukemia. But another very important part of my healthcare experience is that I am a nurse. When we introduced ourselves to the ICU participants, I highlighted my ICU experiences as a family member but not as an ICU and ward nurse. I felt like I was a spy and was there on false pretences! When I listened to participants comment about ICU and ward nurses, it caused me great angst, and I wished I could leave the room in order to get a grip with my feelings. Later, I was able to debrief with my team and talk about how difficult it is to be a healthcare professional and a PaCER. Was it possible to be both? Should we be honest and tell participants if we are health professionals too? Would that really influence how participants share in focus groups and interviews?

When my research colleagues and I conducted our own internship project, my feelings and experiences as a nurse came to play once again when we were doing focus groups and interviewing participants. I had a milieu of emotions that surfaced from being frustrated with patient and family participants’ lack of understanding of nurses’ workload and how nurses are frustrated with high nurse-patient care ratios and not being able to give the care they so wish they could provide. I also was overwhelmed when I heard participants describe the inadequate care they or their family member received. I often felt embarrassed, saddened and wanting to apologize for what happened to them. I found it hard wearing two hats; one as a family member and the other as a nurse. I know there are other PaCERs who are nurses and are able to manage both roles when doing PaCER research. This is an important issue I need to address in order to be comfortable in the PaCER role.

The PaCER program experiences made me realize there is something very special and powerful with patient and family stories. All participant information my colleagues and I collected, presented us with a mutual desire to respect and honour their stories and be responsible to accurately describe and report them in our research findings with the goal of improving patient and family care within our health system. It is that important goal that will guide me throughout my research pursuits as a PaCER.

Peter Oxland

The years of 2012 and 2013 had a major impact on my increased involvement in healthcare. In October 2012, my wife died in Intensive Care after 1 year of increasingly poor health and a very late diagnosis of a nasal cavity tumour. In February 2013, I joined the Critical Care Strategic Clinical Network (CC SCN) Core Committee as a Family Advisor. In the summer of 2013, I retired from my professional career, having worked as part of IBM Canada Ltd. for 33+ years, the last

10 as a management consultant. Since joining the CC SCN, I took part in the committee's monthly meetings, yet increasingly wondered what positive impact I could help make to help in Intensive Care.

My internship experience has me reflecting on many things I have learned:

I sense most AHS Patient and Family Advisors are involved because of their own personal story/experience. When told well, these stories/experiences can catch the attention of audiences – however, I've learned they do not provide the required evidence to support change. The opportunity to have these Advisors see how the collective voice of patients and families can be understood through PaCER to create evidence, and be taken seriously by traditional scientific research to help inform change, is exciting. I heard about PaCER at a late 2013 AHS Patient Engagement Reference Group Meeting and it piqued my interest.

The CC SCN Scientific Director asked me to review two research grant submissions in the fall of 2013 to ensure they had good focus on engaging patient and family members. I found neither did and suggested he contact the PaCER leads. The result was hastily-included paragraphs in both submissions on how PaCER would be used to understand what is important to patients and families who have been in Intensive Care. There may be value with PaCER leveraging existing working relationships between Patient/Family Advisors and their SCN's Scientific Directors.

I appreciated our project team working closely together, where we understood and leveraged our different skills. I believe this resulted in very good project results, plus contributions and an enjoyable experience by us all.

I found the creative analysis another PaCER team used with their narrative interviews very interesting and valuable. I liked the way they created collective stories/experiences based on the personal stories/experiences they heard, feeling that they brought to light the major themes identified, yet kept things somewhat personal.

Although initially hesitant about having weekly reviews with our PaCER mentors, I found them very helpful . Our mentors had the ability to understand quickly what we were doing and provide valuable, insightful suggestions for us to consider.

I recall the frequent guidance we received during our PaCER training to forget about (or 'park') our personal experiences, as it may negatively impact our project work. Each of our personal experiences is part of who we are as a person and in most cases, the reason why we are involved with PaCER in the first place. I sense it may be important to recognize our personal experiences better than is currently being done within a PaCER project. My ICU experience helped with the credibility I (and I think our whole team) had with our project participants, that we have ‘been there’, allowing them to be honest, frank and safe when sharing their stories/experiences. Without my personal experience in ICU, I doubt Critical Care would have reached out to PaCER for help with this project, and I doubt I would be involved with AHS Critical Care and PaCER.

Going forward, I hope to find ways to use the results of this (and any) PaCER research, along with that of any other research having been conducted, to help inform our Critical Care Patient and Family Centred Care (CC PFCC) Collaborative Committee what is important to patients, family members and ICU staff.

I sense traditional scientific research teams tend to have limited success in having research results lead to change in patient and family member care. I’m hopeful (with some confidence) that with the support of the CC SCN Scientific Research team, CC SCN leadership and the ICU front line staff we have on our CC PFCC Collaborative Committee, we will be in a position to have research results inform what changes should be considered to make ICU better. Each resulting area of focus decided upon will have a multi-disciplinary working group to plan for the change.

It was clear to me our project’s participants want to be involved in helping to improve ICU. I am hopeful that with the support of the Critical Care SCN Scientific Research team and PaCER leadership, we will have the ability to ethically determine who among these past (and future) research project participants may be interested in being involved in future Critical Care PFCC projects.

The skills developed during my internship, plus my enjoyable working relationship with my PaCER team members, have me wondering how we can continue to work together on future projects. I respect and appreciate their offer to accept our internship project within the world of Intensive Care, and would like to consider being involved in a future project in their area of greatest interest.