

## **Engaging Patients and Families to Help Research Inform and Advance Patient and Family Centered Care in Critical Care**

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The Authors have nothing to disclose.

## SYNOPSIS

ICU patient, survivor and family member engagement is evolving in both critical care medicine and research. The results of two qualitative critical care research projects led by ICU survivors and family members illustrate how patient-partner research training can inform the critical care community of meaningful priorities in the traumatic ICU context. The resulting creation of a prioritized list of critical care research topics builds further on the construct of patient-centered care.

## KEY WORDS

critical care medicine, intensive care unit, ICU, research, engagement, patient-oriented research, patients, family members, patient-centered and family-centered

## KEY POINTS

- Research engagement of ICU survivors and family members can mean involvement in generating project ideas, writing grants, leading and/or participating in qualitative research, committees, interviews or focus groups, guideline production, result dissemination and authorship.
- Family members and ICU survivors' lives are indelibly changed by their ICU experience. Making sense of this disruption can be achieved by purposeful narrative.
- Enabling and framing qualitative research initiatives provides credible feedback to critical care providers suggesting alternative and user-centred, rather than provider-driven, ways to offer ICU and post-ICU care.
- The qualitative projects highlighted herein suggest patient and family member-led qualitative research is feasible.

## INTRODUCTION

Critical care units became integrated in hospitalized services in the 1970s. For the next three decades, caring for the critically ill focused almost exclusively on resuscitative medical care, both in clinical practice and in the literature. In the early 2000s, the first Society of Critical Care Medicine (SCCM) sponsored family-centered guidelines<sup>i</sup>, updated in 2017<sup>ii</sup>, described clinical observations from the bedside, bringing family experience and distress into the critical care literature. Subsequently research corroborating the concept of Post-Intensive Care Syndrome, affecting both patients and families, further supported the importance of conceptually recognizing and researching family-centered care<sup>iii</sup>. These first high-profile publications educated practitioners as to the collateral damage, and consequences, of the trauma experienced by families, highlighting the inextricable relationship between the quality of caring in the ICU and these sequelae<sup>iv</sup>. In parallel, a Canadian led the first of many longitudinal studies<sup>v</sup> pointing out the physical and psychological sequelae experienced by patients<sup>vi</sup> and families<sup>vii viii</sup>. In 2005, ICUsteps, a United-Kingdom-based intensive care patient support charity, reflected how ubiquitous and international post-intensive care caregiver challenges were, and highlighted the need for support on this difficult journey. Integrating patients and family members in research was first instigated by individual researchers focusing on patient preferences for level of resuscitation<sup>ix</sup>, and among critical care physicians asking about values and creating decision-making tools<sup>x</sup>. Patient preferences for which outcomes are studied became a collective effort in the partly critical care-based TechValueNet, where patient involvement was framed not only in research participation but as an innovative model of knowledge translation. Collaborative research networks such as the Canadian Critical Care Trials Group formally created a family advisory board within its organization in February of 2015. Other researchers led Delphi-based inquiries to explore research priorities relevant to critical care survivors<sup>xi</sup>.

Finally, inviting patients and families in the writing process of professional guidelines; establishing recommendations determining their care is a recent phenomenon. The Council of Medical Specialty Societies (CMSS) requirements mandate they be informed by families, caregivers and other stakeholders; however these recommendations do not define either process or level of involvement<sup>xii</sup>. The American Society of Critical Care Medicine acquiesced the requests of the chair of the Family-Centered Guidelines and the vice-chair of the Pain, Agitation, Delirium, Immobility and Sleep (PADIS)<sup>xiii</sup> to integrate patients and families as full partners. Including

patients and family members on these work teams was an important recognition of the importance of acknowledging the input of ‘end-users’ of critical illness. Patients rank-ordered proposed topic lists provided by each guidelines’ expert panel, reordering priorities and in the process disrupting the traditional paternalistic self-attribution of the ‘expert’ role long espoused by clinicians. Additionally, the qualitative literature including focus groups, surveys, and interviews of patients and families describing their experience were considered in the Family Guideline evidence review and analysis.

The call for meaningful patient and family engagement in health care and research is increasingly mandated by clinical healthcare organizations, as well as becoming a prerequisite for research funding. Meaningful patient and family engagement requires health practitioners and researchers to actively partner with patients, families, and organizations to advance care and research. These partnerships and opportunities herald a departure from paternalism and the traditional disease-centered approach to health care and acknowledge, as has been proposed by the Canadian Critical Care Trials Group, that patients and families hold unique expertise and experiences that can improve clinical care and research<sup>xiv</sup>. Many factors motivate patient partnership, including influencing and improving health care<sup>xv</sup>. Engagement in this context exceeds participation as an informant, and is instead a true partnership in the construct of advances or improvements in care.

As an example of this we describe our experiences with a collaborative patient engagement process. In 2014, University of Calgary and Alberta Health Services Department of Critical Care Medicine researchers initiated the “*Reassessing Practices in the Daily Care of Critically Ill Patients: Building Capacity and Methodologies to Identify and Close Evidence Care Gaps*” project. In conducting this study of the gaps in daily care of critically ill patients across the province of Alberta, Canada, the Research Team involved former ICU patients and family members as partners.

In this paper we describe:

- Two qualitative research projects led by qualitative-research-trained former patients and family members working with a local critical care research team,
- How this exercise informed what is meaningful and important through ICU survivor and family member testimonials, and
- How this activity brought together the critical care community, including actionable items such as a prioritized list of critical care research topics.

The following are highlighted in this paper:

- A novel research model involving peer-to-peer qualitative researchers, to *understand the ICU experiences of former ICU patients and family members* (Study A),
- Use of a second peer-to-peer qualitative research study to *understand the experiences of patients and family members being transferred from ICU to a hospital ward* (Study B), and
- *Personal perspectives* shared by the authors.

## **STUDY A: UNDERSTANDING PATIENT AND FAMILY EXPERIENCES IN THE DAILY CARE OF CRITICALLY ILL PATIENTS**

### ***Background***

Healthcare systems want to engage a broad spectrum of stakeholders to help identify and define patient care priorities for research and quality improvement<sup>xvi xvii</sup>. Meaningful engagement of patients and families in this process can be challenging and limited literature supports how this can best be implemented<sup>xviii</sup>. Barriers can be particularly salient in critical care, where contextual circumstances are often overwhelming<sup>xix</sup>. Evidence suggests that patients and families may be more open to sharing their experiences with those who have had a similar experience.

### ***Objective***

This study was part of a larger initiative designed to identify and close patient care gaps in intensive care units (ICU) in the province of Alberta, Canada. The objective was two-fold:

- To understand the experiences of critically ill patients and their families, and

- To identify opportunities to improve the quality of ICU care for patients and families.

## Methods

### Design

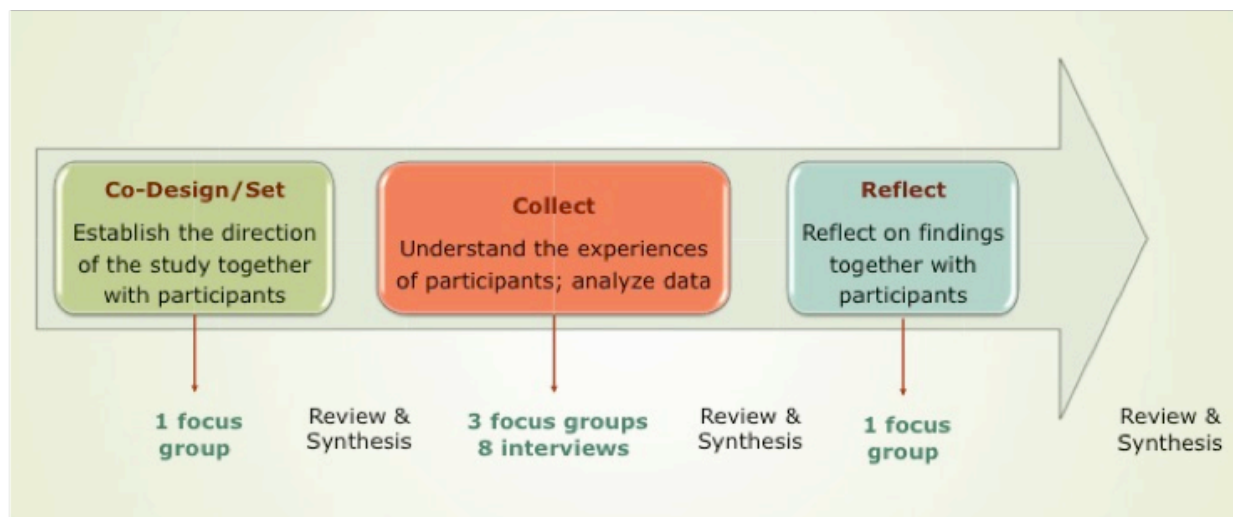
We utilized a novel program called Patient and Community Engagement Research<sup>xx</sup>, (PaCER)<sup>xxi</sup>, to fully engage ICU patients and family members in this study. PaCER trains patients, family, and community members to conduct peer-to-peer qualitative research. Overseen by university faculty, and a PaCER Lead, PaCER researchers apply a three-phase framework: co-design/set, collect, reflect, to examine patient experiences from varied perspectives (Fig. 1). Participatory grounded theory, iterative data collection and analysis cycles are used to test emerging data and cultivate a collective patient voice.

### Participant Recruitment

ICU patient care managers, social workers, and physicians provided information on the study to previous ICU patients. PaCER recruited 32 participants from 13 adult ICUs in 7 large and smaller urban centers in Alberta, Canada. Participants were former ICU patients and family members of ICU patients. Patients had a variety of admitting conditions, treatments, lengths of stay and outcomes.

### Data Collection, Analysis and Research Method

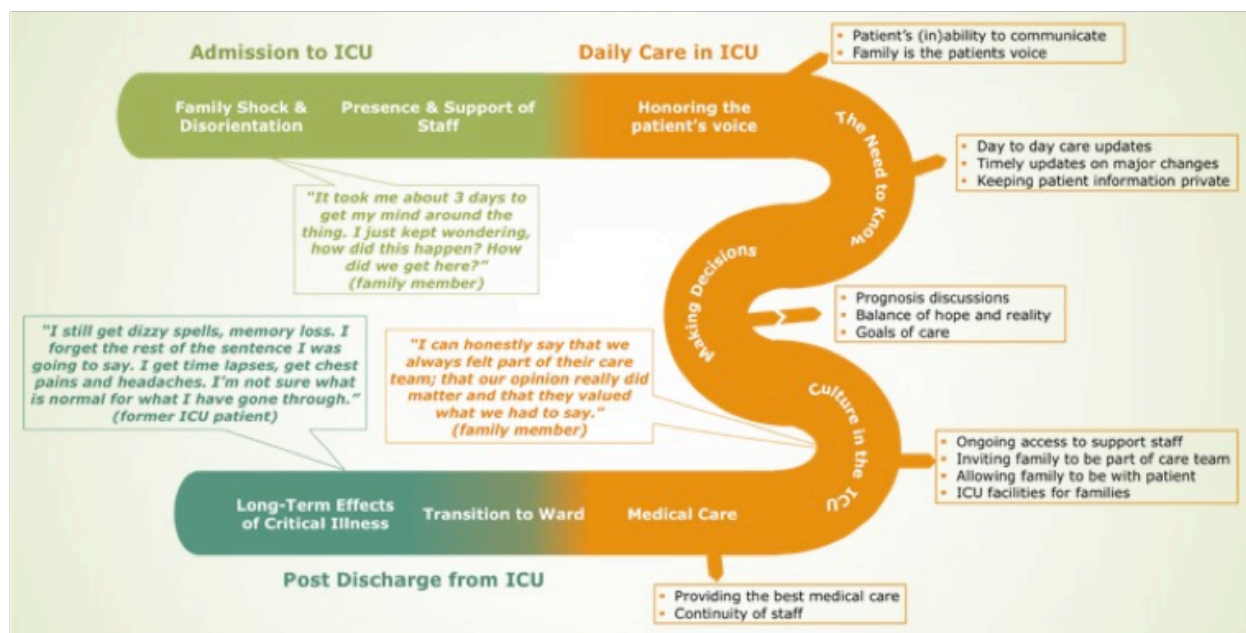
Audio recordings of focus groups and interviews were transcribed verbatim. After coding by PaCER researchers, participants were invited to review, comment on, validate and challenge emerging themes. All transcripts were also independently analyzed by two academic qualitative researchers blinded to the PaCER results.



**Fig. 1.** PaCER research method. (*Adapted from* Gill M, Boulton D, Oswell D, Oxland P. Understanding patient and family experiences in the daily care of critically ill patients. Patient & Community Engagement Research (PaCER) report; 2014; with permission.)

## Results

Thematic analysis produced 18 themes tied to three phases collectively describing ‘The ICU journey’: 1) Admission to ICU, 2) Daily Care in ICU, 3) Post Discharge from ICU. Themes within Daily Care (n=14) were grouped into five higher order themes which together highlighted a fragility of trust and comfort between patients and family members, and ICU providers (Fig. 2). Comfort and trust fluctuated with perceived appropriateness and quality of interactions (Fig. 3).



**Fig. 2.** The ICU journey. (Adapted from Gill M, Boulton D, Oswell D, Oxland P. Understanding patient and family experiences in the daily care of critically ill patients. Patient & Community Engagement Research (PaCER) report; 2014; with permission.)

Key findings in each phase of the journey were:

- **Admission to ICU:** When first entering the ICU, family members usually experience extreme shock and disorientation. What is “normal” for staff feels “alien” for families. Families also outlined their need for support in getting clear, consistent, and complete information. Most patients had little memory of this experience.
- **Daily Care in ICU:** Family members need to be updated (day to day, in a timely manner when major changes in patient’s health occur and family is absent), heard, and involved in decisions to feel well cared for, respected, and valued. Interactions with the care team and efforts to establish comfort and trust in the ICU were integral to the notion of a community of caring. Families indicated the importance of honoring the patient’s voice when a patient was unable to speak for themselves. Readily sharing information regarding their loved one’s health increased decision-making capacity and their sense of agency. Actions that left the family feeling less confident and in control included lack of visiting access and perceiving not being welcomed as an important part of the care team. These features, whether perceived or real, increased family member anxiety and reduced trust in the care team.
- **Discharge from ICU** was traumatic, expectations were not well understood, concerns were not always addressed, and symptoms sometimes went untreated. Specifically, inadequate preparation time for the move, perceived poor communication between ICU and ward providers, and limited knowledge on the part of ICU providers as to what would happen after ICU discharge were distressful. Discharge home triggered anxiety about physical, cognitive, and mental health symptoms suggestive of Post ICU Syndrome. Patients and families were hesitant to rely on their primary care physicians, whom they perceived to have limited knowledge of the long-term sequelae of critical illness. A sense of abandonment and confusion as to where to turn for information was common.

Patients and families depended on ICU providers to invite them into a trusting and comforting relationship. These relationships are fragile, with trust being threatened with a single event or negatively perceived comment, regardless of the team’s prior trust-building efforts. Patients and families perceive ICU providers as a team and need all team members working together for them to feel confident in their ongoing care.

## Parallel Analysis

Academic researchers identified similar themes, yet produced different interpretations and recommendations. This was most striking in interpretations of patient/family - provider communications. For example, PaCER understood participant's need for improved communication skills as improving provider's active listening skills while academics interpreted this as improving the clarity of the content that provider's deliver. The academic researchers also categorized the data into groupings of content in contrast to the PaCER's organization of the data into a temporal journey.

Parallel levels of frustration in 'being heard' are described in the very different context of primary care, where hurry/ the need for throughput often leave patients or families with unanswered questions and anxiety. Vulnerable individuals can perceive their sense of agency is threatened, as has been described in European qualitative ICU patient experience studies<sup>xxii</sup>. Sites such as Discutons Santé (DS, [www.discutonssante.ca](http://www.discutonssante.ca)), a webbased tool created to foster active patient engagement during medical consultations<sup>xxiii</sup> improves communication quality, chronic disease outcomes<sup>xxiv</sup>, and promotes information recall. Patient focus groups confirm its value through stress reduction, empowerment and improved partnering with the healthcare provider with these empowerment initiatives significantly improving patient and family satisfaction. Physician interpretation, as in the PaCER example, differed from patient and family perspective. One communication dimension related to the significant reduction in medication and diagnostic errors is a hereto unexplored aspect of communicating with patients in families in the critical care setting.



**Fig. 3.** Patient and family zone of comfort and trust over time. (Adapted from Gill M, Bagshaw S, McKenzie E, et al. Patient and family member-led research in the intensive care unit: a novel approach to patient-centered research. PLoS ONE 2016;11(8):e0160947.)

**Recommendations** for improvement made by patients and family members:

1. Provide a Dedicated Family Navigator
2. Increase Provider Awareness of the Fragility of Family Trust
3. Understand the Importance of the Mode, Tone and Content of Provider Communications
4. Improve ICU to Hospital Ward Transitions
5. Inform Patients about Long-Term Effects of Critical Illness

### ***Key Messages:***

Patients and families identified nine themes, 14 sub-themes, and five specific recommendations, based on their experiences in intensive care. Study results have since been used to inform and prioritize research and quality improvement initiatives in critical care across Alberta. Actionable guidance to enhance front-line ICU patient and family-centered care has included:

- ICU Family Presence Guiding Principles
- A 24-hour ICU Supportive Care Bundle for patients and families
- A reconciliation process involving ICU clinicians and the results of this study (from ICU patients and families) which identified the five top priorities for critical care research going forward:
  1. Delirium screening
  2. Family presence & effective communication
  3. Transitions of care from ICU to hospital ward
  4. Transitions of care between ICU providers
  5. Early mobilization.

### ***Lessons Learned:***

Comfort and trust, and appropriate interactions with ICU providers, are very important components in the common, collective ICU experience of patients and family members. Many opportunities exist for improvement in ICU care and research. Patients and family members are valuable partners for research and quality improvement. Engaging patients and family members as researchers is a viable strategy if institutional investments exist and patient and family centered care prioritized. This approach could serve as a model for quality improvement across other settings. The PaCER method can identify opportunities for improving healthcare that academic researchers and frontline healthcare providers may not recognize or adequately elicit from research participants. Further, PaCER exemplifies the empower stage along the International Association for Public Participation (IAP2) spectrum and should be considered a viable model to foster public engagement in research and Quality Improvement across other settings.

## **STUDY B: PATIENT AND FAMILY EXPERIENCES WHEN MOVING FROM THE INTENSIVE CARE UNIT (ICU) TO A HOSPITAL WARD**

### ***Background***

ICU patients are among the sickest hospitalized patients. They receive constant, one-on-one, specialized care in an environment utilizing life support technologies and significant resources. When ICU patients' conditions improve and they no longer require this intensive care, they are usually transferred to a hospital ward. Here they become 'one patient among many'<sup>xxv</sup> and the nurse to patient ratio switches from one-to-one to one-to-many<sup>xxvi</sup>. Moving vulnerable patients to an environment with limited resources is a high-risk medical transition and, due to the demand for ICU beds, patients may be given little advance notice of their move<sup>xxvii</sup>.

In Canada, over 250,000 patients will be transferred from ICUs this year. Many patients will suffer adverse consequences during their transition, and 18,000 patients will be readmitted to the ICU<sup>xxviii</sup>, an indication of both the risk associated with transfer and the challenges inherent to transitions within the healthcare system. Patients and their families often find the transition from ICU to a hospital ward very challenging, given the fear of the unknown and the dependency fostered in the critical care setting<sup>xxix</sup> in contrast to hospital wards, which have fewer resources and lower nurse to patient ratios.

### ***Objective***

To understand the experiences of patients and family members when a patient is moved from the ICU to a hospital ward.

## ***Methods***

### **a) Patient Engagement Framework**

Patients and family members led all aspects of the study. The project was led and conducted by PaCER interns, as part of their one-year internship, supported by PaCER leadership.

### **b) Data Collection**

Two five-hour focus groups were held with participants using the Co-Design/Set (e.g., establishing the direction of the study) and Reflect (e.g., to reflect on findings) method. Seventeen individual interviews were held with former ICU patients and family members.

### **c) Participant Recruitment**

Personal contacts, a PaCER lead, a research coordinator, and hospital recruitment posters helped recruit 22 participants from five adult ICUs in Alberta located in two cities (Calgary, Edmonton). ICU patients and family members of ICU patients participated. Patients had a variety of admitting conditions, treatments, lengths of stay and outcomes.

## ***Results – Experiences and improvement opportunities***

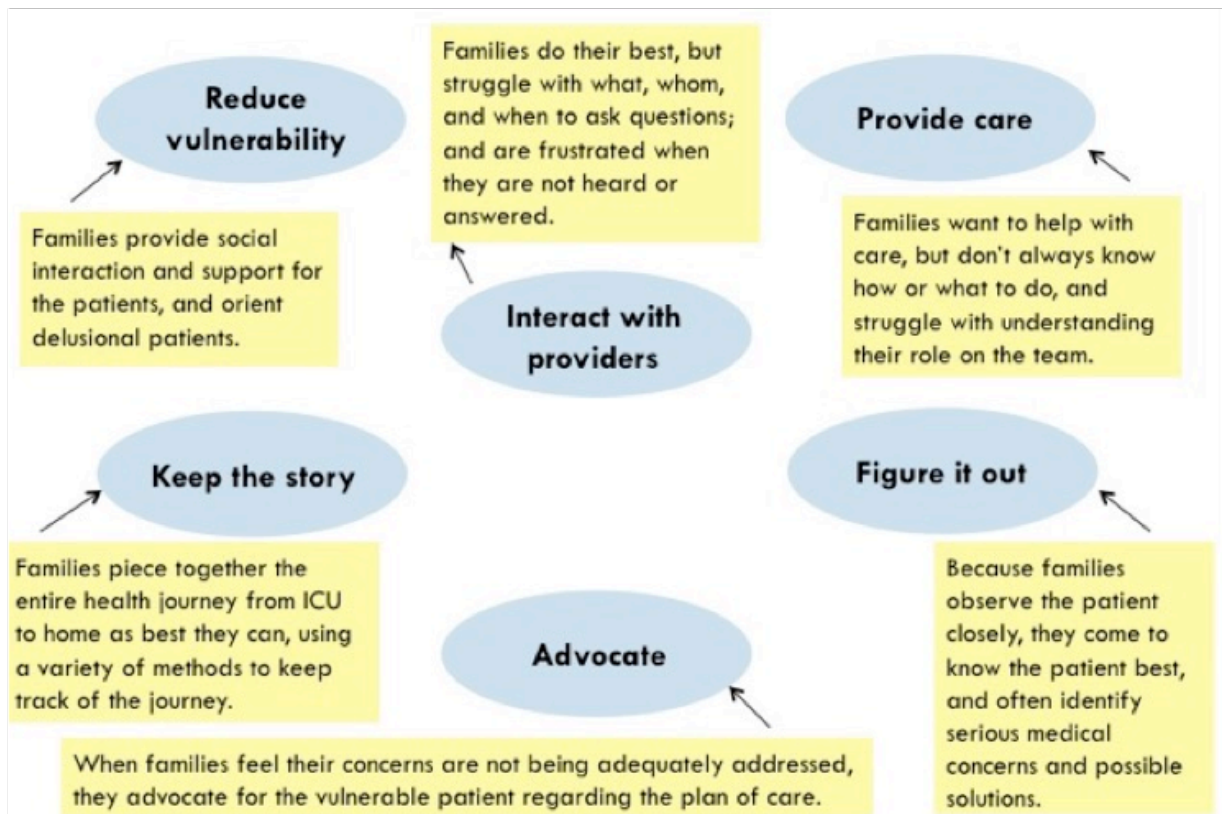
Of the 17 themes, six described actions undertaken by families in response to a health emergency in the ICU, hospital ward, and/or elsewhere in the patient's health journey. We grouped these six themes in the 'What Families Do' category (Fig. 4). Each of these actions can be viewed as an independent activity that families may have felt compelled to undertake to help care for the patient. Whether or not the families undertook these activities was dependent upon whether they perceived they needed to, and whether they were able to intervene in the patient's care. Essentially, families do what they feel needs to be done.

Four themes in the category What Families Do describe actions that families undertook to directly help with the patient's care and recovery: Reduce vulnerability, Provide care, Figure it out and Advocate, and Keep the Story. When these actions occurred in isolation from ICU providers, their efficacy is perceived by family members as being limited. When these actions are combined with effective interactions with the staff, as depicted in Fig. 5, this capacity builds in a synergistic way, leading to a category we called Positive Outcomes.

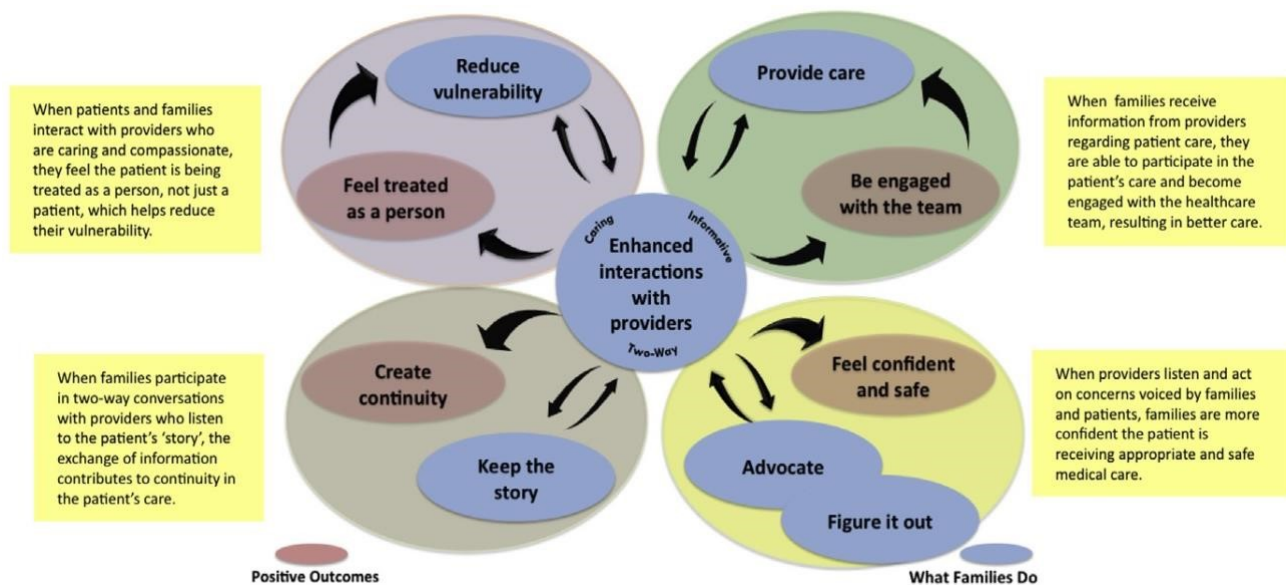
There are four main synergistic loops in Fig. 5, with each loop having Enhanced interactions with providers at the center. Most patients and family members probably do not experience these loops in isolation of each other, which reinforces the importance of the common elements of all three loops – two-way, caring and informative interactions with the ICU providers.

We observed that patients and family members found it very difficult to view the transfer experience from ICU to the hospital ward separately from their overall health journey, because other experiences in their journey influenced their perception of the transfer experience. Fig. 6 illustrates how The Hospital Transfer Experience is a subset of their challenging health journey.



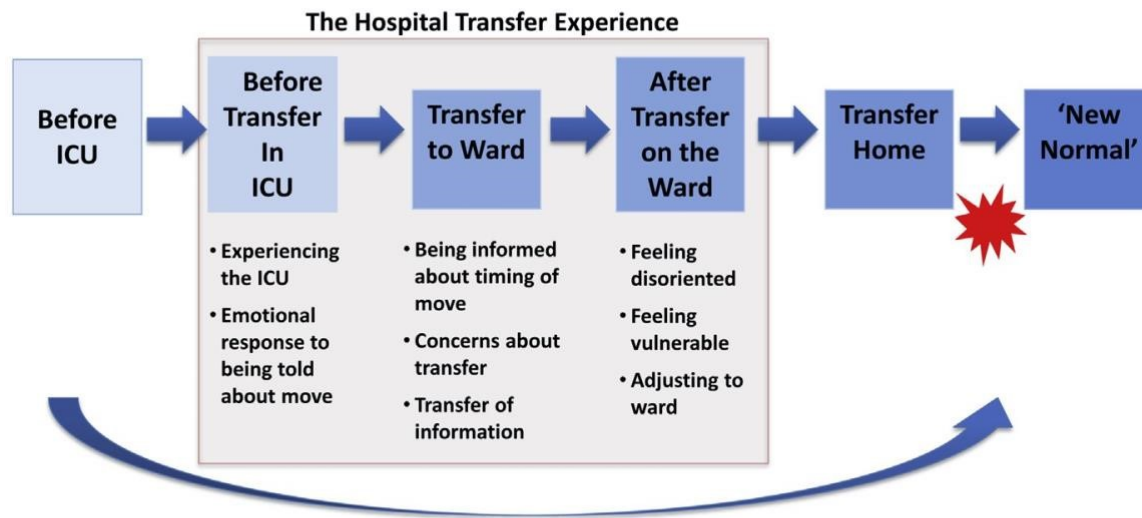


**Fig. 4.** What families do. (Adapted from Boulton D, Oswell D, Oxland, P. Patient and family experiences when moving from the intensive care unit (ICU) to a hospital ward. Patient & Community Engagement Research (PaCER) report; 2015; with permission.)



**Fig. 5.** Model for engaging families and patients. (Adapted from Boulton D, Oswell D, Oxland P. Patient and family experiences when moving from the intensive care unit (ICU) to a hospital ward. Patient & Community Engagement Research (PaCER) report; 2015; with permission.)

# Creating Continuity in Health Journey



**Medical care takes place in separate specialized units**

**Families create continuity between units by  
Keeping the Story**

**Fig. 6.** The hospital transfer experience. (From Oswell D, Oxland P. Patient and family experiences with critical care: Patient & Community Engagement Research (PaCER) project PowerPoint presentation; Critical Care Research Transitions in Care meeting. Sept 2018; with permission.)

## **Recommendations**

Six major recommendations were identified to help improve the Transitions of Care from ICU to a hospital ward:

1. Keep patients and family members informed about the move
2. Provide orientation to the ward
3. Facilitate family's attempt to keep the patient's story
4. Improve provider, patient and family communications
5. Provide dedicated navigator/advocate
6. Engage families with the care team

## **Conclusion**

The overarching message was to shift towards more meaningful engagement of families with the healthcare team, by **valuing the benefits of family expertise and by giving them a role**. Studies addressing the healing power of the narrative<sup>xxx xxxi</sup> and highlighting critical care caregivers as enablers for distressed families (sense-making theory<sup>xxxii</sup>) are early descriptors of patient and family engagement benefits in research as in clinical care. Embracing diversity is universally beneficial<sup>xxxiii</sup>, yet also requires hard work, genuine engagement rather than lip service, and trust. As with other models where multidisciplinary partners engage in mutually respectful construction with a common goal, the benefits are likely to be numerous and multifaceted. How to best approach patient and family engagement, and an assessment of potential risks, should also be studied.

## SUMMARY

### *Discussion*

The critical care research team used a novel approach that involved patients and family members as qualitative researchers in two projects to better understand patient and family member ICU experiences and identify opportunities for improvement. Former ICU patients and family members played different roles in different parts of the projects. Study participants described shared experiences in their "ICU journey", and when moving from the ICU to a hospital ward. Ways to improve the experiences of ICU patients and family members were identified. Analyses by independent academic qualitative researchers in one project identified similar themes and suggestions for improvement<sup>xxxiv</sup>, but through a health system rather than patient and family lens. These projects have helped to better understand what is important to ICU patients and family members, and together with the experiences of ICU providers, contributed to create a prioritized list of critical care research topics going forward, and had former ICU patients and family members meaningfully involved in the projects.

### *The Role of Patients and Family Members in Research*

Research studies have traditionally been conducted by health researchers. Members of the public with a healthcare experience usually serve as research subjects. Our experience shows that patients and families can play different, valuable roles when empowered to help with a research project.

Supporting members of the public in a qualitative research methodology training program is a major investment, which aims to mirror a long-term commitment to patient and family-centered care. Our experience suggests this high level of qualitative research involvement is feasible and of interest to patients and family members, who value the opportunity to contribute to projects that can improve healthcare.

What former ICU patients and family members contribute should be shaped by their interests, abilities and available energy and time. Locally, the critical care scientific research team embraced this involvement from grant writing, as project participants (committees, interviews, focus groups), dissemination of results, publications - which informed the critical care community as a whole, and provided meaningful opportunity to the former ICU patients and family members involved.

### *Lessons for the Care of the Critically Ill*

The two studies discussed in this paper illustrate the value of understanding the experiences of former ICU patients and family members, and the identified opportunities to improve their experience. Patients and family members share common experiences and initiatives to address identified opportunities for improvement can lead to improved care.

When a patient is in the ICU, an important covenant of trust is created between the family and ICU providers. In Study A, families described how to foster that relationship; recognize their stress and disorientation when the patient is admitted, proactively orient them, invite them to be active members of the care team (i.e., by attending rounds, helping at the bedside as appropriate) and engaging them in bidirectional communication and decision-making. In Study B, it was found that when a patient is transferred from ICU to a hospital ward, patients and family members experience distressing reactions to this transfer. They do not know what to expect, are hesitant with the transfer occurring, and family members wish to participate and have a role in the transfer process.

A recurring theme in both studies was ... "*What is normal for health care providers is not normal for patients and families.*" Peer-to-peer qualitative researchers have the ability, through their lived ICU experience, to gain the trust of ICU patient and family member study participants when facilitating interviews and focus groups. Our experience is the creation of this safe, trusted, comfortable space for vulnerable former ICU patients is very important and leads to an honest and rich sharing of their experience.

Many opportunities for improving the experience of ICU patients and family members were identified in the two studies. When reconciled with the experiences of ICU providers, opportunities were created to identify and prioritize a dialogue which can lead to future research initiatives and eventually improved care.

## **AUTOBIOGRAPHICAL PERSONAL PERSPECTIVES**

### **Peter Oxland**

Our ICU experience was the most challenging time in our lives. My wife's deteriorating health over 12 months led to the late diagnosis of a rare malignant nasal-cavity tumor masquerading as chronic sinusitis<sup>xxxv</sup>, expanding to involve her eyes and her brain. Over a 30-day period she was admitted to neurology, received cancer treatment, discharged, taken to emergency and admitted to ICU where she died 6 days later.

Soon after she died, I became a critical care family advisor with different committees focused on enhancing ICU care. Over time, I shared 'Our Story' with audiences - a humbling, meaningful experience. Becoming a qualitative researcher with the University of Calgary's Patient and Community Engagement Research (PaCER) program, involved a 1-year internship and helping conduct two qualitative research projects (studies A & B).

My experiences highlight considerations when engaging former ICU patients and family members in research:

- The often sacred stories of former ICU patients and family members should be acknowledged and honored. Balancing and leveraging these with the collective voice learned through qualitative research is also very important.
- ICU stays have seriously impacted the quality of life post-ICU for many patients and family members. Many interview and focus group participants, even after 2-3-4 years, had not shared their ICU experiences with others. Better post-ICU psychosocial, and peer support, could make a very positive difference in the quality of their lives.
- ICU patient and family member experiences are often life-changing. During interviews and focus groups, I consistently felt their interest in wanting to 'give back' to ICU, yet ethics did not support their continued involvement. These passionate people are under-utilized ICU resources whose continued involvement should be supported
- Qualitative researchers with a lived experience similar to participants can provide safety and comfort in interviews and focus groups - especially with former, often vulnerable, ICU patients who struggle with their health and well-being. Our 5-hour focus groups involved participants sharing experiences, often the first time, resulting in very meaningful, supportive and intimate gatherings. In two individual scientific research teamled meetings, two patient-partners found 1) noisy environments, and 2) an overbearing presence of researchers. The researchers neither anticipated nor perceived these elements as threatening patient-partner sense of safety, highlighting how essential sensitizing is to ensure patient safety and comfort. Constant validation of a sense of safety is thus essential for this process so patients truly engage and choose to participate.
- The public becoming qualitative researchers is novel, as is the contrast with academic qualitative researchers as shown in the different interpretations of next steps in this work. Performing data analysis from a patient/family (PaCER) versus from a health-system lens (academic researchers) is very valuable.
- Public research capacities (interests, abilities, time, energy) vary, are often not well understood, resulting in the research team not knowing how each member of the public can best contribute to research. Meaningful involvement deserves focus and good stakeholder communications.
- Creating published papers (important academically) does not seem balanced with regular/effective dissemination of research results. Proactively creating a visually appealing summary for each research project, and using this with front-line providers/clinicians and the public would help ensure research results are used, plus help create awareness and generate enthusiasm.

Becoming a qualitative researcher and witnessing the increased involvement of former ICU patients and family members within the critical care community has been humbling, and a learning experience. I hope the collective voice of former ICU patients and family members is never forgotten, always considered, and when combined with that of ICU providers/clinicians, leads to positive changes in care.

### **Nadine Foster**

I have had the privilege to receive outstanding lifesaving ICU care. I have also been through unexpected end of life care with my mother in the ICU. As an interesting coincidence, my mother and I were both the only RNs in the family. My mother was once a charge nurse in the ICU where she died. As a child, I remember my mother spoke

about her patients always being asleep and her work uninterrupted by family visits. This happened in the 1970s. ICU care has come a long way from her nursing days. Patients are more alert now and families act as partners in care.

While I am no longer a practicing RN, my previous career and my personal ICU experiences left me longing to contribute back to health care in a different way. I began simply by telling my own story. In my experience, telling my own story had an impact, particularly to front line staff who often don't know what happens to a patient when they leave the ICU. Sharing in this way can ideally express how grateful patients and families are for the difficult and important work they do every day. It also allows patients and families to discuss where things might have gone wrong, or what they'd like to see change. While I began by sharing my own story of being both a patient and a family member in the ICU, I came to the realization there are common themes in the collective voice. This collective voice can be a powerful tool to help the critical care community understand ways in which to improve outcomes. These are the stories and the voices that weren't heard when my mom was still working. Much to the credit of the critical care community, we are more welcome now.

In 2015, I joined my first patient and family centered care group and have now sat on various similar committees in an effort to share patient and family views. I have been involved in the creation of tools for best practices for family presence, the MyHealth.Alberta ICU Delirium information page for patients and families, among many others.

Perhaps the most meaningful way to contribute is being involved in research. It's very innovative to involve members of the public and embed them throughout the research process. This can help to guide research in the direction of what patients and families feel is important, while allowing patient and family partners to collaborate with multiple stakeholders to ensure all voices are heard and the best, most useful, ideas are put forth.

In both of the studies outlined in this paper, the results and recommendations that emerged resonated strongly with me. I was able to relate to them personally, and they both helped me to see that my own story shares so many critical elements with the collective voice. Those results have been used to set priorities for projects and research provincially and have largely dictated the initiatives I have been a part of to date. It has been delightful to be a part of watching patient priorities become important research topics.

### **Kirsten Fiest**

Collaborating with former ICU patients and family members in critical care research is a privilege. Instead of doing research for patients, we are now doing research with patients; this shift has led to exciting research, including the studies described above. There is still much for researchers to learn, including how best to evaluate patient engagement initiatives. As we focus on conducting research to ultimately improve patient care, we should continue to engage patients and family members in ways they find meaningful. This can be achieved through an open and honest dialogue; expectation setting for all parties is essential to successful patient engagement in research. Though the research process is at times slow, I continue to be delighted by the progress we are making in this area.

### **Yoanna Skrobik**

Patients have been the primary source of what I learned about critical care over many years of practice. In this effort as in other dimensions welcoming their input in a safe, respectful environment is humbling; I echo the sense of privilege. I look forward to witnessing tangible change from an avuncular but paternalistic to deliverable 'patient-centered' critical care.

## **SUMMARY**

Many former ICU patients and family members are indelibly changed by their ICU experiences. Opportunities exist to meaningfully involve these individuals in many ways, including in research projects.

The recurring theme in both studies discussed in this chapter can be summarized as: *"What is normal for health care providers is not normal for patients and families"*, an insightful and important lesson to acknowledge, respect and consider. ICU patient and family member experiences offered valuable perspectives of what is important to them through these two studies, and differed from insights brought forward by providers.

It is also important to acknowledge and respect the value of involving many different stakeholders (e.g., ICU providers/clinicians, researchers, patients and families, etc.) in research projects. Involving the public in such projects requires focus and effort by the research team, with the opportunity over time to develop a trusted, valued working relationship, ultimately leading to improved ICU care.

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