

A novel patient and community engagement research method to understand patient and family experiences with critical care

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on behalf of the Critical Care Strategic Clinical Network

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Introduction

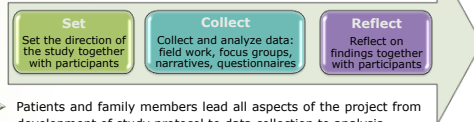
- Healthcare systems are engaging stakeholders to help identify priorities for research & quality improvement
- A key challenge has been how to best engage patients and families
- Evidence suggests that patients and families are more open to sharing their experiences with those who have had a similar experience
- PaCER (Patient and Community Engagement Research) is a novel approach to patient and family engagement, in which:
 - Former patients, family members, and community members receive formal research training
 - Collaborative research is conducted by, with, and for, patients and family members

Study Objective: To test whether this approach can be used to describe the ICU experiences of critically ill patients and their families, and to identify opportunities to improve ICU care.

Methods

Patient Engagement Framework

- Three-phase patient engagement framework:



- Patients and family members lead all aspects of the project from development of study protocol to data collection to analysis

Participant Recruitment

- Patient care managers, social workers, and physicians recruited participants from 13 ICUs
- Participants had a variety of admitting conditions, treatments, lengths of ICU stay, and outcomes
- ICUs included large urban and small regional centres located in 7 cities

Data Collection

- 5 focus groups & 8 interviews with patients recovered from critical illnesses & family members of surviving & deceased patients



Qualitative Research

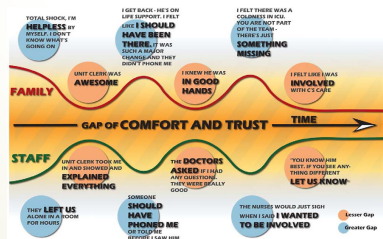
- Qualitative analyses using phenomenology, a method designed to understand the human experience as it is lived
- Strategies employed to ensure validity of analyses:
 - PaCERs examined & articulated biases prior to research
 - Use of member checks
 - Discussions regarding emerging data, coding and thematic categories with project working group

Results

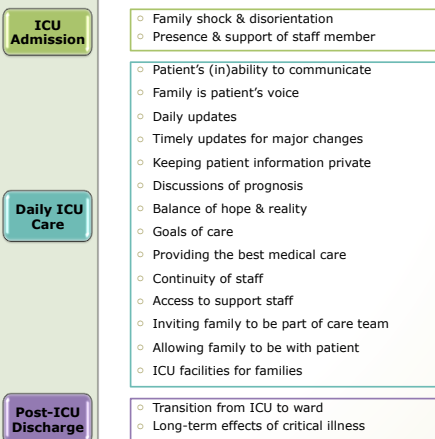
Participant Characteristics

Characteristics	Participants (n=32)
Female	17
Age (median years)	54
Patient / Family	
Patient	11
Family of surviving patient	14
Family of deceased patient	7
Duration of patient ICU stay (median days)	21
Type of ICU	
Tertiary care	16
Community, large urban centre	14
Community, small urban centre	10

Comfort and Trust: Key Contributors to ICU Experience



Thematic Content of ICU Experience



Five Recommendations for Improvement

- Provide a dedicated family guide, liaison or navigator**
 "It would really help if there was one person, the same person, to explain what is going on ... someone who knows the system - who knows how ICU works."
- Improve transition from ICU to hospital ward**
 "In ICU the nurses are on 12 hour shifts and you just go through that transition once a day... Then you go onto the ward and most of those nurses work 8 hour shifts so you are going through this transition two or three times a day... you don't know them, they don't know you. How can you feel secure then?"
- Improve provider communication skills**
 "Anyone who had anything to do with that particular nurse noted that she was not sensitive, she did not communicate well and that threw everyone off."
- Increase provider awareness of the fragility of family trust**
 "We camped out for nine days - we took over the waiting room - at night there were four of us sleeping. We had no trust."
- Inform patients about long-term effects of critical illness**
 "There was no information about what would happen when he got home. He didn't know what he was able to do. We need some indication of what you might notice."

Discussion

- Patients and family members are an untapped resource for research and quality improvement
- Comfort and trust are central components in the common, collective ICU experience of patients and family members
- 5 opportunities for improvement were identified and will inform quality improvement initiatives

Conclusion

- Engaging patients and family members as researchers is viable strategy
- This approach could serve as a model for quality improvement across other settings