



A modified Delphi process to identify clinical and research priorities in patient and family centred critical care



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ABSTRACT

Purpose: To identify elements which enable patient and family centred care (PFCC) in the intensive care unit (ICU) and priorities for PFCC research.

Materials and methods: We engaged a panel of multidisciplinary stakeholders in a modified Delphi process. Items generated from a literature review and panelist suggestions were rated in 3 successive rounds on a scale from 1 to 7. Median score was used to rate each item's priority, with 5 or more indicating "essential priority," 4 or 5 "moderate priority" and 3 or less "low priority." Interquartile range (IQR) was used to measure consensus, with IQR of 1 indicating "high" consensus, 2 "moderate" consensus, and 3 or greater "low" consensus.

Results: Six items were rated essential elements for facilitating PFCC with high consensus (flexible visiting hours, family participation in bedside care, trained family support person, interventions to facilitate continuity of care, staff education to support families, continuity of staff assignments). Three items were rated essential research topics: interventions to facilitate continuity of care following ICU discharge (moderate consensus), family participation in bedside care (low consensus), and decision aids for end of life decision-making (low consensus).

Conclusions: Stakeholders identified clear and distinct priorities for PFCC in clinical care and research, though there was greater consensus for clinical care.

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1. Introduction

Many adult intensive care unit (ICU) patients are incapacitated by illness and rely upon relatives, friends, or substitute decision makers to speak on their behalf [1,2]. It is upon this "family" that the burden of medical decision-making falls, predisposing them to fatigue, anxiety, and post-traumatic stress disorder (PTSD) [3–6]. Critical illness also impacts ICU survivors, with risks of cognitive dysfunction, functional impairment, PTSD, and decreased quality of life long after hospital discharge [7–9]. Recognition that the experience of receiving care for

an illness, in addition to the disease itself, impacts patients and families has led to calls to shift from disease-oriented health care towards more patient and family centred care (PFCC) – care which is responsive to individual patient and family preferences, needs, and values [10–12].

PFCC requires understanding the needs and perspectives of patients and families, who can be engaged across the health care spectrum, from direct bedside patient care, to higher level organizational design, and to governance and policy making [13]. Within the ICU, Olding et al. developed a framework for classifying patient and family involvement, ranging from passive (family presence) to active (direct contributions to care) [14]. Strategies to engage patients and families across these dimensions have demonstrated improvements in communication, satisfaction [15–17], PTSD symptoms [16], and reductions in the provision of unwanted, non-beneficial treatment [15].

Despite potential benefits, there remains uncertainty about which elements of care best facilitate PFCC, as guideline recommendations are

Abbreviations: ICU, intensive care unit; PTSD, post-traumatic stress disorder; PFCC, patient and family centred care; IQR, interquartile range.

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based on moderate to low quality evidence [18]. Identified barriers to PFCC in the ICU include lack of clinician awareness of such practices [19], and concern that efforts to engage patients and families may impede other aspects of clinical care [20]. More research is needed to better understand how incorporating PFCC practices impacts patient outcomes, family outcomes, and processes of care. Even less evidence exists to guide researchers working in PFCC as to where to direct their efforts. While research priority-setting exercises have been done in the critical care setting, few have focused on PFCC [21]. As PFCC aims to impact the experiences of patients, families, and staff, there is a pressing need for broad stakeholder engagement that includes all members of the healthcare team. Further, it remains unclear whether or not priorities are consistent between countries or regions. Therefore, we engaged representatives from key Canadian stakeholder groups in a modified Delphi process to i) identify elements of care believed to facilitate PFCC in the ICU, and ii) to guide development of a set of research priorities for PFCC in the ICU. These priorities could then be used to provide investigators with direction for research that will expand the evidence needed for ongoing improvements in PFCC within the ICU.

2. Materials and methods

A modified Delphi process was performed according to a protocol which was reviewed and approved by the Hamilton Integrated Research Ethics Board prior to conducting the study. The Delphi process is well recognized as a method to develop consensus among experts or stakeholders, originally created by The RAND Corporation [22]. Panel members are polled anonymously in a series of ‘rounds’ during which they have the opportunity to rate the importance, relevance, or validity of statements related to the topic of interest. Key aspects of the Delphi process include ensuring the anonymity of participant results; feeding information back to participants after each round, and pre-specifying criteria for consensus and stopping the process [23,24]. ‘Modified’ Delphi process refers to any Delphi process that varies from the original RAND procedures, including the use of online polling [25].

There are no guidelines outlining how researchers should determine the number of rounds in a Delphi process. Most investigators use two or three rounds, as participant attrition increases with successive rounds of polling [23]. Similarly, there is no clear consensus about how many panelists are required, with the recommendation that a sufficient number to adequately represent stakeholders should be balanced with higher attrition rates and pragmatic challenges of coordinating larger groups. Most published Delphi processes include 15 to 20 panelists, and very few include >50 [25,26]. Given these considerations, we chose 3 rounds of online polling for our Delphi process over a period of 6–9 months and a target of 30 participants.

2.1. Panelist selection

We invited an interdisciplinary group of knowledge users and experts by email to participate as panelists. Panelists were chosen to represent key stakeholder groups involved in providing or receiving ICU care, including physicians (Canadian Critical Care Society - 6 members); nurses (Canadian Association of Critical Care Nurses - 6 members); respiratory therapists (Canadian Association of Respiratory Therapists - 3 members); physiotherapists (Canadian Physiotherapy Association - 2 members); occupational therapists (Canadian Association of Occupational Therapists - 3 members); social workers (2 members); spiritual care workers (2 members); patients (3 members) and family members (3 members). Panel members were nominated by their respective organizations or were invited from the investigator’s institutions. We invited patient and family member representatives who had previously agreed to participate in PFCC research. Online webinars were used to outline the study purpose and methods to patient and family representatives.

2.2. Item generation

An initial item list was generated from suggestions made by panel members using an online bulletin-board system, supplemented by items contained in a guideline for supporting families in the patient-centred ICU [27]. Participants could suggest, discuss, and modify items using the bulletin board system over a period of 6 months, after which time the existing items were collated for online polling.

2.3. Data collection

For each round of polling, panelists were sent an email with a link to the online system [28]. Participants rated each potential PFCC item using the following questions:

- How important is [this topic] as an element enabling PFCC in the intensive care unit?
- How important is [this topic] as a priority for future PFCC research in Canada?

We used a seven-point scale to gauge panelist responses to each item, with 1 indicating ‘‘Not at all important,’’ 3 indicating ‘‘slightly important,’’ 5 indicating ‘‘moderately important,’’ and 7 representing ‘‘extremely important.’’ Individual polling items were listed in random order for each participant to minimize question order bias [29]. At the end of the first round of polling, participants were given the option to suggest topics for inclusion in the final two rounds of polling. To reduce redundancy, we grouped new suggestions when proposed by more than one panelist. Recognizing the need for flexibility when polling a diverse group of stakeholders, we allowed two months for panelists to complete each round, with reminder emails sent at approximately two, four, and six weeks following initiation of the round.

2.4. Data analysis

After each round, we calculated basic descriptive statistics for each item. In the second and third rounds, panelists were presented with a summary of the polling results from the previous round for each item. Following the third round of polling, we categorized aggregate panelist ratings independently by their average level of importance (central tendency) and level of panelist consensus about the importance (variation around the central tendency) to develop overall priorities. We summarized panelist ratings of item importance as overall ratings of priority, with items having median scores >5 as an ‘essential priority,’ 4 or 5 as ‘moderate priority’ and 3 or less as ‘low priority.’ Data items with an interquartile (IQR) range of 1 were categorized as having ‘high’ consensus; IQR of 2 ‘moderate’ consensus, and IQR of 3 or greater ‘low’ consensus.

3. Results

3.1. Participant characteristics

Panelist characteristics are listed in Table 1. A total of 28 (93%) panelists completed the first round of the Delphi process, 26 (87%) completed the second round, and 27 (90%) completed the third and final round of polling. One patient and one family member who initially agreed to participate did not respond to invitations to join in the polling.

3.2. Topic selection and classification

Our initial list of topics included 12 items, supplemented by two additional items suggested by panelists during the first round of polling (Table 2). Items ranged across the levels of patient and family engagement described by Olding et al., from most passive to most active: one item (7%) encouraging family presence, five items (36%) related to families receiving care and having care needs met, five items (36%) related to communicating and receiving information, one item (7%) related to

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