Experiences and needs of families with a relative admitted to an adult intensive care unit: a qualitative systematic review protocol

Kate Kynoch • Cara Joyce Cabilan • Annie McArdle

Nursing Research Centre and the Queensland Centre for Evidence-Based Nursing and Midwifery: a Joanna Briggs Institute Centre of Excellence, Mater Misericordiae Limited, Brisbane, Australia

Review question/objective: The objective of the proposed review is to determine the best available qualitative evidence to guide healthcare workers when providing care and support for families of relatives in an adult intensive care unit (ICU). The specific objective is to explore the experiences and needs of families with a relative in an adult ICU.

Keywords Critical care; experience; family; family needs; intensive care unit

Background

The admission of a critically ill patient to an intensive care unit (ICU) has long been identified as being an exceptionally distressing life event for both the patient and their family.1-7 It is usually unexpected and sudden, whereby families might suffer uncertainty and shock that may precipitate familial disequilibrium.8,9 It has been suggested that the patient’s response to intensive care management and treatment, and subsequent recovery is dependent on the family’s coping abilities during this traumatic time.6,9-12 However, families have been shown to develop high levels of acute and chronic stress, anxiety and depression when confronted with this situation.2,3 As well as experiencing extreme emotions such as fear, guilt, distress and helplessness.6 These reactions may have a short and long-term impact on the family’s societal and economic lives.8 For example, during this time family members have reported changes in their social and physical activity, eating and sleeping routines and their responsibilities within the family. These necessary psychosocial adjustments have led to significant changes in the roles of individuals within the family unit to reflect new responsibilities involving children, home duties, household finances and the particularly unwelcome responsibility of making healthcare decisions for their critically ill loved one.13 This emotional chaos occurs as a backdrop to the fear of the potential death of their loved one.6 Responses to these changes can include the long-term impact of posttraumatic stress disorder, which can negatively affect quality of life causing social isolation, relationship problems, employment and health issues.2,14

Families have to quickly adapt to this unforeseen and new situation, while being in a state of turmoil, concerned about their loved one and struggling with their own fear of the outcome.6 As well, the ICU may be far from home and the environment can be a technologically bewildering experience for families in which the routines, rules, staff, equipment and sounds are unfamiliar and complex.8,13 Much of the effort to date in defining the needs of ICU families stems from the seminal work of Molter16 who developed the instrument, Critical Care Family Needs Inventory (CCFNI). This tool identifies the most important needs of families with a relative in ICU as its development has been used widely, in its original and adapted form, to define the needs of intensive care patient relatives. In the late 1980s and early 1990s, Leske,17 using the CCFNI, further categorized the needs of ICU families into five distinct domains: (1) assurance, (2) proximity, (3) comfort, (4) support, and (5) information.

The uncertainty and ambiguity of the patients’ often fluctuating condition leads families to adapt by displaying an intense need for information, emotional support and the opportunity to
participate in the physical care of their loved one. Alvarez and Kirby suggested that families cope with the situation by seeking out information because they are frightened by what they don’t know. This universal and ostensibly greatest need has been established amongst several different populations. Families want truthful and consistent information that is delivered in an understandable way frequently throughout the ICU admission. In their qualitative research, Bond et al. found that families wished to be told the facts about their loved ones’ condition, even if it clashed with or indeed compromised their need for hope.

It is axiomatic that emotional support is a primary need as well. Coulter reported similar findings to the study by Keenan and Joseph above in her grounded theory research in which families expressed a need for information. Information regarding the patients’ condition and prognosis, and about the staff and environment were described as a significant need of families. Alvarez and Kirby concurred that this need for information was consistently reported as paramount. Lam and Beaulieu suggested that families are prepared to be present at the ICU, the ICU waiting room also allows for a supportive atmosphere in which families can talk with others experiencing a similar crisis.

Several researchers have discussed the family’s need for involvement in their relative’s physical care while a patient is in ICU. Bond found that families were prepared to be present at the ICU for a long duration during the day and night to be able to provide some physical care to their loved one and were willing to assist with basic care of their relative such as bathing. This created a feeling of inclusion, which potentially could provide an opportunity to witness the patient’s progress (or otherwise) by giving further insight into the situation that verbal or written reports cannot convey to worried relatives. Azoulay et al. believe that participating in the physical care of their loved one engenders a reminder of life before the crisis and restores the emotional attachment. Lam and Beaulieu also concur that this activity maintains the emotional attachment. Being intimately involved in these physical care creates empathy with the nursing, medical and allied staff members, yields a feeling of usefulness and familiarity in an otherwise alien environment, and potentially benefits the decision-making process. Al-Mutair et al. suggest that family participation in bathing, linen changing and pressure care can be extended to include family presence during invasive procedures, even resuscitation, to fulfill the need for providing care and feeling involved.

Nurses caring for patients in ICU are also caring for the families of their patients. Research however suggests that relatives do not always perceive that they are being cared for, and that their needs are not always assessed correctly by ICU nurses. It is also suggested that care for relatives is based on traditional role interpretations rather than nurses’ intuition, practical experience and perceptions of family needs, much less evidence-based research. A systematic review of the qualitative literature will provide nurses and other healthcare professionals in the ICU with an opportunity to understand and prioritize families’ needs and experiences in a profound way which in turn might translate into more empathetic and reflective care and the development of appropriate support interventions for families.

Apart from those aforementioned, researchers and reviewers have identified other concepts, themes and issues that have become evident in qualitative research such as consistency of information, developing coping mechanisms, satisfying personal needs, retaining hope, compassion and relationships with ICU nurses. However, although a search of relevant journals and sources (JBI Database of Systematic Reviews and Implementation Reports, the Cochrane Database of Systematic Reviews, PubMed, CINAHL and PsycInfo) revealed several systematic review and protocols on the qualitative experiences of families with a relative in an adult ICU, no systematic review with the objective to explore the experience and prioritize the needs of families with a relative in ICU was found. Therefore this systematic review...
will provide a concise description of the experiences and needs of families with a loved one in intensive care, giving healthcare providers the necessary understanding to deliver high quality and exceptional care to both ICU patients and their families. This in turn will possibly reduce potential adverse effects of stress.

Inclusion criteria

Types of participants

The current review will consider studies that include any family members (including children) of adult patients admitted to an ICU. Families of patients with any clinical condition, length of stay or outcome will be included. For this systematic review, family will be defined as any person visiting the patient who is affiliated by birth or marriage. Members of the immediate family include spouses, parents, brothers, sisters, sons and/or daughters. Members of the extended family include grandparents, aunts, uncles, cousins, nephews, nieces, siblings-in-law and/or step relatives.

Phenomena of interest

The current review will consider studies that investigate the experiences of families with a relative admitted to an adult ICU.

Context

The context of this review will be ICUs in any acute adult healthcare settings.

Types of studies

The current review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, feminist research and discourse analysis.

Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Third, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English language (due to limited funding for translators) from 1980 to present will be considered for inclusion in this review. This timeframe was selected on the basis of the retrieval of previous studies carried out in the early 1980s that investigated the needs of families with a relative admitted to an ICU. This broad timeframe will ensure that all relevant studies on this topic are included in the systematic review.

The databases to be searched include PubMed, CINAHL, PsycINFO, Embase and Web of Science. The search for unpublished studies will include ProQuest Dissertations and Theses. Initial keywords to be used will be:

- Critical care OR critically ill OR intensive care OR intensive therapy OR ICU
- Family OR families OR relatives OR family needs
- Experience OR perception OR meaningfulness
- Qualitative research.

Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity before inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data extraction

Data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories are then
subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. The findings will be presented in a narrative form, where textual pooling is not possible.

References

Appendix I: QARI critical appraisal instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Is there congruity between the stated philosophical perspective and the research methodology?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Is there congruity between the research methodology and the research question or objectives?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Is there congruity between the research methodology and the methods used to collect data?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Is there congruity between the research methodology and the representation and analysis of data?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Is there congruity between the research methodology and the interpretation of results?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Is there a statement locating the researcher culturally or theoretically?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Is the influence of the researcher on the research, and vice-versa, addressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Are participants, and their voices, adequately represented?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Overall appraisai: □ Include □ Exclude □ Seek further info. □

Comments (Including reason for exclusion)
Appendix II: QARI data extraction form

JBI QARI Data Extraction Form for Interpretive & Critical Research

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviewer</td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td></td>
</tr>
<tr>
<td>Journal</td>
<td></td>
</tr>
<tr>
<td>Record Number</td>
<td></td>
</tr>
</tbody>
</table>

Study Description

Methodology

Method

Phenomena of Interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete: Yes □ No □
## Systematic Review Protocol

<table>
<thead>
<tr>
<th>Findings</th>
<th>Illustration from Publication (page number)</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Unequivocal</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Extraction of findings complete: Yes [ ] No [ ]