ICU Trajectory for Families: A Scoping Review Protocol

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Abstract

Objective: The purpose of this scoping review is to map research knowledge about the family members experiences, including healthcare care received, during the entire trajectory of patients' admission to an adult Intensive Care Unit (ICU) and up to one year following their discharge from ICU or death.

Introduction: There is increasing awareness of the impact of a patient's critical illness on family members. Therefore, there is a need to map the emerging body of literature to clarify around publication trends including central findings of studies, temporal focus of studies, conceptual definitions, research designs and measurement tools used. To advance science in this area, it is critically important to identify where gaps in knowledge and methodology persist.

Inclusion criteria: Research articles of any design that focus on the family experience and care with more than 50% of study participants being adult family members of patients who had admission to an Adult ICU.

Methods: The scoping review will conform to the JBI methodology for scoping reviews; the developed search strategy will be performed in MEDLINE and CINAHL. Publications in English, French, German and Dutch between January 2000 to March 2023 will be included due to an international group undertaking the review. Study selection will be detailed using the PRISMA-ScR flow diagram to delineate identification, screening and included studies. Data will be extracted by the research team, collated, analysed and themed regarding the research questions and objective of the review.

Keywords: Family Nursing, Family Care, Follow-Up Care, Intensive Care Unit

Introduction

It is acknowledged that a relative's critical illness event and subsequent admission to an intensive care unit (ICU) is an intensely stressful experience for family members (Rhoads et al., 2022). In the intensive care community, there has been increasing awareness of and concern for the association between higher stress levels in family members and the risk of developing long term negative psychological, emotional, physical, and relational consequences (Davidson et al., 2012; Harvey & Davidson, 2016). In response, there has been a proliferation of research conducted exploring various aspects of family member experiences (Twohig et al., 2015; Williams et al., 2021) and testing of interventions at differing timepoints of the family member's critical care journey (Bohart et al., 2022; Rodríguez-Huerta et al., 2019). Indeed, during the last decades, the breadth of research relating to family experiences of critical illness is diverse and spans a variety of foci and methodological approaches to the generation of knowledge. This scholarly activity has produced welcomed and important understandings about family member experiences of a relative's critical illness event with subsequent development of promising interventions. However, this rapid expansion of knowledge has led to a need to synthesize the research landscape and to identify components of experience that have received scholarly attention and where gaps in knowledge yet remain.

The diversity of research approaches to explore family experiences of a relative's critical illness event is evident. For example, when exploring family members' psychological response and coping behaviours during and after a critically ill relative's admission to a critical care unit, Rückholdt et al., (2021) found symptoms of anxiety persisted for family members in the months after discharge and coping strategies changed over time. Family member satisfaction with care and involvement in decision-making during a relative's critical illness event was evaluated by Khan et al., (2022) who found family members to be highly satisfied with care yet encountered barriers to their involvement in decision making. Lived experiences of family members during a relative's ICU admission were explored by McKiernan & McCarthy (2010) who found family members have a need for information, a need to be physically close to their critically ill relative, a need for support to help them cope with the experience, and a need to make sense of the critical care admission. Frivold et al., (2015) completed a phenomenological inquiry exploring a specific element of the critical illness event: the families' experiences of being cared for by the critical care team. In this study, Frivold et al. (2015) found that family members assume a role of receiving information and care but are also active agents in a participatory role during patient care and decision making.

The trajectory of care for a patient in the ICU is illness specific and may include a short or long stay in the ICU, transfer to a speciality critical care unit (such as neurological ICU), and subsequently lead to long term recovery or death of the patient. Research has focused on family experiences at different timepoints of the critical illness trajectory such as interhospital transfers that occur in early phases (Burns et al., 2023; Karlsson et al., 2020; Mackie et al., 2014), and at later phases such as the experiences of family members in the year after a relative's discharge from an intensive care unit (Ågård et al., 2015). Furthermore, research has explored more context specific areas such as the family member's experience of bereavement within the cardiac intensive care unit (Erikson et al., 2022) or the experience of bereavement both within the ICU and beyond into the months following the relative's death (Bandini, 2022).

Professional support is often accompanied by informal support managed by family members. From the first signs of illness to recovery and the end of life, family members play a key role in the patient's journey, because many patients in ICU are not able communicate. However, the population of interest in many critical care research studies is not uniformly

defined, but uses a variety of terms, such as the caregiver's experience (Kreitzer et al., 2020), the family caregiver's experience (Johnson et al., 2019) and the family's experience (Abdul Halain et al., 2022), or in an interchangeable way (Basile et al., 2021).

For many years, nurses and other health care professionals have advanced important work to meet the needs of family members of hospitalized, critically ill patients. Many interventions or initiatives have been developed and evaluated, such as a nurse-led family support intervention during the ICU admission (Naef et al., 2022), an integrated health and social care intervention for caregiver anxiety in the year after a critically ill relative's discharge from hospital (McPeake et al., 2022), impact of daily written updates on satisfaction and psychological well-being of family members of critically ill adult patients (Greenberg et al., 2022), and the impact of flexible ICU visiting policies on family member anxiety and satisfaction (Rosa et al., 2021).

There have been efforts in the critical care community to increase coherence around family care in this evolving area of research, with reviews on specific components proliferating. Coombs et al. (2020) completed a systematic review to determine factors that influence family members' perception of safety in the intensive care unit and (Imanipour et al., 2019) performed a systematic review describing the family members' experiences of a critically ill adult relative's ICU admission. Delirium in critical illness and the family member's experiences has been attended to in an integrative review conducted by Assa et al.(2021). Damanik & Chen (2021) mapped family needs during a relative's admission to ICU in their scoping review and interventions for post intensive care syndrome. Zante et al. (2020)explored post intensive care syndrome of families in a systematic review noting the importance of communication. More recently, Kiwanuka et al. (2022) completed a mixed methods systematic review of nurse-led family interventions and family outcomes.

The COVID-19 global pandemic and associated public health restrictions has also received attention from nursing scholars. Terzi et al. (2022) evaluated the needs of family members of people admitted to critical care units during the time of pandemic associated visitor restrictions and Kentish-Barnes et al. (2021) conducted a phenomenological inquiry exploring the lived experiences of family members of patients who died in ICU because of COVID-19. Additionally, Fernández-Martínez et al. (2022) completed a systematic review to better understand interventions implemented during the COVID-19 pandemic to support family centred care in ICU.

The significant amount of scholarly activity has resulted in an acceleration of the development of awareness related to the family members' experiences of a relative's critical illness event. However, the level of scholarly attention and development in this area has led to a loss of coherence of this knowledge landscape. The purpose of this scoping review is to map the full breadth of research about the trajectory of family experiences and care received during a relative's admission to an adult ICU and up to one year following their discharge from ICU or death. In doing so, persisting gaps in knowledge in this area will be identified to direct future research endeavours. According to Munn et al. (2018) a scoping review method will help to achieve this goal.

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and *JBI Evidence Synthesis* was conducted and no current or underway systematic reviews or scoping reviews on the topic were identified. One systematic qualitative review was identified. Kynoch et al. (2021) explored the experience and needs of families with a relative admitted to an adult intensive care unit. This differs from the aim of the present scoping review which is to

identify all types of research and explore results, not only during ICU stay, but beyond discharge (up to one year).

Review question

The purpose of this scoping review is to map research knowledge about the trajectory of family experiences and care received during a relative's admission to an adult ICU and up to one year following their discharge from ICU or death. Specifically, the research questions are:

- What are the publication trends relating to family experiences and the critical illness trajectory?
- How are the terms 'family' or 'family member' used and defined?
- What types of research designs are used and, where relevant, what measurement tools are utilised regarding family experiences and care?
- What phenomena are investigated (e.g., intervention, evaluation, implementation, experiences, perceptions) related to the trajectory of family care?
- What are the family experiences and care at different points along the patient trajectory?
- What interventions and support are utilised by healthcare providers when caring for families during this trajectory?

Methodology

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (Peters et al., 2021) and in line with the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018).

Search strategy

The search strategy will aim to locate both published and unpublished studies. A three-step search strategy will be utilized in this review. First, a limited search of MEDLINE (PubMed) and CINAHL (EBSCO) (Appendix 1) was undertaken to identify articles on the topic. Second, the titles, abstracts, and index terms from this initial search were analysed and used to develop a full search strategy for both MEDLINE (PubMed) and CINAHL (EBSCO) (Appendix 1). Lastly, the reference lists of all included sources of evidence will be screened for additional studies which match the inclusion criteria.

Studies in English, French, German or Dutch, published between January 2000 – March 2023 will be considered for inclusion. These languages were included based on the research groups' international expertise. Selection for time frame sampling was guided by the publication of Needham et al. (2012) where the consequences of critical illness events for patients and family members were first described as post intensive care syndrome (PICS), and post intensive care syndrome- family (PICS-F) respectively. To capture contemporary research leading up to Needham et al., the years 2000-2023 were selected.

The final search will be completed in MEDLINE (PubMed) and CINAHL (EBSCO) and grey literature searching in Dissertation and Theses (ProQuest), Grey Literature Report, and relevant resources listed in the CADTH Grey Literature Searching Checklist.

Study/Source of evidence selection

Following the search, all identified citations will be collated and deduplicated in a citation management platform before being imported into Covidence software (a review management platform). Titles and abstracts will then be screened by two independent reviewers for assessment against the review's inclusion criteria. The full text of potentially relevant sources will be retrieved, uploaded to Covidence, and assessed in detail against the inclusion criteria by two independent reviewers. Reasons for the exclusion of studies which do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer/s. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018).

Data extraction

Data will be extracted from papers included in the scoping review by two or more independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the participants, concept, context, study methods and key findings relevant to the review questions. The draft data extraction form is provided in Appendix 2: it will be modified and revised as necessary. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers will be resolved through discussion, or with an additional reviewer/s. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Data analysis and presentation

Extracted data will be summarized and analysed using thematic analysis. Data from discrete fields in the extraction form (e.g. country of publication, design) will be summarized with frequencies and percentages. Extracted data will be sorted according to study focus, interventions/support and patient/family trajectory. Data will then be inductively and, if appropriate, deductively coded independently by two or more researchers, using a coding guide. Next, codes will be discussed and sorted into preliminary categories and summarized. Finally, for each research question, coding lists and preliminary categories will be reviewed, charted, and further synthesized.

A descriptive summary will be present a narrative of the results, including graphs/diagrams, as they align with the review questions. The scoping review followed the JBI methodology, hence it does not require appraising the methodological quality of the studies (Peters et al., 2021).

Eligibility Criteria

Participants

Inclusion criteria

<u>Family members:</u> Family members, defined as whoever the patient defines as family (Shajan & Snell, 2019; Wright et al., 2019) of the critically ill patient are the primary or main participants in the study (>50% of participants in the study are family members of the critically ill patient). E.g. not the patients, nurses or other healthcare providers describing family members' needs.

Family of an adult patient who has been admitted to an ICU will be included. Patients are defined as critically ill adult patients that have been admitted to an ICU.

Intensive/Critical Care unit has been defined as:

"an organized system for the provision of care to critically ill patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency

based in a defined geographic area of the hospital according to The World Federation of Societies of Intensive and Critical Care Medicine" (Marshall et al., 2017).

Exclusion criteria

Family members of critically ill pediatric patients will be excluded, as well as family members of critically ill patients who are not admitted to an ICU or critical care unit such as patients critically ill at home or in a medical unit and not be transferred to the ICU. Studies in which the main participants (>50%) are not family members of the critically ill patient (e.g. patients, nurses or other healthcare providers describing family member needs) will be excluded as will studies using nurses or other health care providers as proxy informants. While patients are considered a part of the family unit, this scoping review will focus on the care and experiences of the family members of the critically ill patient. Additionally, articles in languages other than English, French, German or Dutch will be excluded.

Concept

Any research methodology relating to a critically ill adult patient's family member (such as their experiences, perceptions, needs, interventions, and care received) during the initial critical illness event and subsequent trajectory up to one year post patient ICU discharge or death.

Context

All geographical locations will be included related to ICU and following through to one year post patient ICU discharge or death. All ethnicities, races and genders will be considered.

Types of sources

This scoping review will consider both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion.

Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, thematic analysis, content analysis, action research and feminist research.

In addition, all evidence synthesis papers, such as systematic, scoping, mixed methods reviews or meta-synthesis, meta-analysis studies and grey literature that meet the inclusion criteria will also be considered, depending on the research question.

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Declarations

The team undertaking this scoping review are committed to equality, diversity and inclusion. The review will strive to find examples of diverse people and communities to inform our research aims. The literature search strategy will enable a diversity of papers to give insight to a variety of perspectives. The scoping review approach means that any key findings that affect the environment for families should be enlightened.

Author contributions

All the authors contributed to the conceptualization of the study. KMP created the search strategy. MB, VdG, AP, KMP and RN contributed to the protocol development specifically, NM, PB, and SE provided critical review of the protocol.

Conflicts of interest

There is no conflict of interest in this project.

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Appendices

Appendix I: Search strategy

Full Search Strategy – CINAHL

Limiters - Published Date: 20000101-20220931

S1	TI "next of kin" OR AB "next of kin"
S2	TI "relatives" OR AB "relatives"
S3	((MH "Family Attitudes+") OR (MH "Family+") OR (MH "Extended Family+") OR (MH "Family Characteristics+") OR (MH "Family Functioning+") OR (MH "Family Relations+") OR (MH "Nuclear Family+")) OR TI (family OR families) OR AB (family OR families)
S4	TI "loved one*" OR AB "loved one*"
S5	S1 OR S2 OR S3 OR S4
S6	((MH "Critical Care+") OR (MH "Critical Care Nursing+")) OR TI "critical care" OR AB "critical care"
S7	(MH "Intensive Care Units+") OR TI ("intensive care" OR ICU) OR AB ("intensive care" OR ICU)
S8	S6 OR S7
S9	((MH "Intensive Care, Neonatal+") OR (MH "Intensive Care Units, Pediatric+") OR (MH "Child+") OR (MH "Infant+") OR (MH "Adolescence+")) NOT ((MH "Adult+") OR (MH "Aged+"))
S10	S5 AND S8
S11	S10 NOT S9

Results: 7672

Appendix II: Draft Data Extraction Form

	Title	Authors	Publication date	Country	Population	Context	Methods	Key Findings
ĺ								