Effectiveness and family experiences of interventions promoting partnerships between families and pediatric and neonatal intensive care units: a mixed methods systematic review protocol

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ABSTRACT

Objective: This mixed methods systematic review examines the effectiveness and family experiences of interventions that promote partnerships between parents and the multidisciplinary health care team in pediatric and neonatal intensive care units.

Introduction: The hospitalization of a child or infant in an intensive care unit can have considerable negative effects on them and their family. Family members can experience increased stress, anxiety or depression and detrimental impacts on quality of life and family functioning. Interventions that promote families as health care partners may improve negative outcomes arising from intensive care hospitalization.

Inclusion criteria: The review will include family members of pediatric or neonatal patients hospitalized in an intensive care unit. It will focus on interventions that promote partnership between families and multidisciplinary health care teams in pediatric and neonatal intensive care units and the family's experiences of these interventions. The outcomes of interest are stress, anxiety, depression, quality of life, family functioning, family empowerment or satisfaction with family-centered care.

Methods: The proposed review will follow the JBI methodology for convergent segregated mixed methods systematic reviews. It will search for published and unpublished studies from eight different sources. Studies will be reviewed by title and abstract and potentially eligible studies will have full text retrieved for further review. Studies meeting the inclusion criteria will be assessed on methodological quality and the data will be extracted. Separate quantitative and qualitative analysis and synthesis will be performed and an overall analysis will be presented.

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Keywords Critical care; family centered care; pediatrics; psychosocial; systematic review

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Introduction

When an infant or a child is hospitalized in an intensive care unit (ICU), there is widespread impact on the family.[1] Family can refer to those biologically related to the child or those who are not but who have a significant relationship with and provide support to the child.[2] This relationship is defined by the patient or, in the case for children, their surrogates.[2] The psychosocial health of the family members can be negatively impacted during an intensive care hospitalization.[1] Post intensive care syndrome can also impact patients leading to mental health, cognitive and physical impairments.[1] It has

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been well described in the literature in relation to adult patients, however, its impact on pediatric patients and their families is poorly described.[1] Nevertheless, up to 60% of children survivors of ICUs experience psychological trauma[3] and 21% to 32% of family members experience acute stress or post-traumatic stress disorder.[4] Other studies have focused on the patient experience,[5] however, the impact on the family should not be ignored. Family-centered care (FCC) concepts have been developing for decades and there has been increasing focus on initiatives to improve the involvement of families in health care and hospitalization.[2] However, the magnitude of involvement depends on how families are empowered to engage in decision-making and care in general. When families are empowered, they are considered true partners of the health care team in the care of the child. Partnership between families and the health care team is defined as the strategies that result in the achievement of FCC and involves active participation in the patient's care and decision-making.[6] The emergence of the concepts of partnership promotes mutually beneficial involvement of patients, families and the health care team in the development, implementation and evaluation of health care.[6] It is suggested that this partnership is required in order to achieve optimal health, care and economic outcomes.[6]

Interventions to improve partnerships between families and health care teams have been implemented, aiming to minimize the detrimental psychosocial outcomes from intensive care hospitalization.[7,8] Due to the considerable impact of ICU stays, various studies have explored interventions to support families. Existing literature includes interventions focused on family integrated care[8] empowerment[7] and mother-nurse partnerships.[9] Reviews of adult patients and their families have reported the effectiveness of interventions that have included diaries,[10,11] family support nurses, information brochures, flexible visiting hours, structured communication and improved comfort measures,[10] and family presence at important events.[11] It has been suggested that there is a need to further examine the benefits of partnerships between families and health professionals.[2]

The development of partnerships within an ICU environment is highly valued by parents, which recognizes the importance of the family relationship in the patient's care.[12] An understanding of the challenges, benefits and acceptability of interventions as experienced by families is necessary to inform health providers in their decision-making concerning optimal interventions for implementation.

A preliminary search of PROSPERO, PubMed, the Cochrane Database of Systematic Reviews and the *JBI Database of Systematic Reviews and Implementation Reports* was conducted to identify potentially similar previous reviews. One qualitative review focused only on the neonatal ICU and included parent and nurse experiences of partnership.[13] Another review focused on pediatric chronic illness, revealing that problem-solving therapy may improve parent mental health.[14] A further systematic review examined infant and parent outcomes from family-centered care interventions in neonatal ICUs, with a majority of studies assessing parent satisfaction and education, with some interventions assessing anxiety, stress or depression.[15] Two review protocols focusing on psychological interventions in the neonatal ICU[16] and family engagement within adult, pediatric and neonatal ICUs were located.[17] To the best of the authors' knowledge, no previous or in-progress reviews focused on the effectiveness and experiences of family partnership interventions were identified. This review will focus on both the effectiveness and experiences of interventions promoting partnership between families and both neonatal and pediatric ICUs incorporating both quantitative and qualitative studies.

Review questions

i) What is the effectiveness of interventions where the health care team collaborates with families as partners in pediatric and neonatal ICUs?
ii) What are families' experiences of interventions where the health care team collaborates with families as partners in pediatric and neonatal ICUs, including benefits and challenges?

Inclusion criteria

Participants

The review will consider studies conducted in the pediatric or neonatal ICU that include families of patients, regardless of the patient's length of stay, diagnosis or treatment outcome. In view of the diversity of contemporary family types across cultures, for this review, family is defined as the patient's surrogates. The family may be biologically related

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or unrelated to the patient. In the pediatric and neonatal ICU context, the family is often the parents and individuals who provide support and with whom the patient has a significant relationship.[2]

Intervention

The quantitative component of the review will consider studies with interventions where the multidisciplinary team partners with families in health care. The multidisciplinary team will encompass members of the health care team providing care to the patient and family, including medical practitioners, nurses, allied health professionals such as social workers, child life specialists, psychologists, and support staff such as chaplains. It will exclude volunteers, other parents and student health professionals. It will incorporate family interventions fostering collaboration,[18] empowerment,[19] active participation, information sharing, choice, respect or dignity.[20] Interventions must occur during intensive care hospitalization but may extend before or after this period. The interventions will be compared with all existing alternative interventions.

Phenomena of interest

The qualitative component of this review will consider studies exploring family experiences of interventions that are conducted in collaboration and partnership with families. This may include the benefits and challenges of these interventions as well as the acceptability or other aspects of the intervention.

Outcomes

The quantitative component of this review will consider studies that include psychosocial or satisfaction outcome measures, such as (but not limited to) stress, anxiety, depression,[2] quality of life,[21] family functioning, family empowerment[19] or satisfaction with FCC. These outcomes should be measured by a validated instrument. Outcomes will focus on the family, but patients' outcomes will also be reported, when available.

Context

The qualitative component of this review will consider studies associated with hospitalization in pediatric or neonatal ICUs. An ICU is 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."[22(p.274)] This may take the form of separate or combined pediatric ICUs and neonatal ICUs that are located in any type of hospital. It will include studies conducted in any country.

Types of studies

This review will consider quantitative, qualitative and mixed methods studies. Quantitative studies will include both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. Qualitative studies will include designs such as phenomenology, grounded theory, ethnography, action research and feminist research. Mixed method studies will only be considered if data from the quantitative or qualitative components can be clearly extracted.

Studies published in English or French will be included. Studies published from 2000 to the present will be included to represent current practices and because of changes in FCC, such as increased visiting times, that occurred around this time.[13]

Methods

The proposed systematic review will be conducted in accordance with the JBI methodology for convergent segregated mixed methods systematic reviews.[23]

Search strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of PubMed and CINAHL was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE (Ovid) (see Appendix I). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. The reference list of all studies selected for critical appraisal will be screened for additional studies.

Information sources

The databases to be searched include: MEDLINE (Ovid), CINAHL (EBSCOhost), Embase (Elsevier), PsycINFO (Ovid) and Web of Science Core Collection (Clarivate).

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Sources of unpublished studies and gray literature to be searched include: ProQuest Dissertations and Theses and DART Europe E-theses Portal. For quantitative studies only, ClinicalTrials.gov and WHO International Clinical Trials Registry Platform will also be searched via the Cochrane Library (Cochrane).

Study selection

Following the search, all identified citations will be collated and uploaded into EndNote vX9 (Clarivate Analytics, PA, USA) and duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review using Rayyan (Qatar Computing Research Institute, Doha, Qatar). Potentially relevant studies will be retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).[24] The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion, or with a third reviewer. The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram.[25]

Assessment of methodological quality

Quantitative studies (and quantitative components of mixed methods studies) selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from JBI SUMARI.

Qualitative studies (and qualitative components of mixed methods studies) selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from JBI SUMARI.

Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The results of the critical appraisal will be reported in narrative form and in a table.

All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis, where possible. Results of the assessment of methodological quality will be reported and taken into consideration when discussing the final integrated findings.

Data extraction

For the quantitative component, data will be extracted from quantitative and mixed methods studies (quantitative component only) included in the review by two independent reviewers using the standardized data extraction tool in JBI SUMARI. The data extracted will include specific details about the populations, study methods, interventions and outcomes of significance to the review objective.

For the qualitative component, data will be extracted from qualitative and mixed methods studies (qualitative component only) included in the review by two independent reviewers using the standardized JBI data extraction tool in JBI SUMARI. The data extracted will include specific details about the population, context, culture, geographical location, study methods and phenomena of interest relevant to the review objective. Findings and their illustrations will be extracted and assigned a level of credibility.

Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data synthesis and integration

This review will follow a convergent segregated approach according to the JBI methodology for mixed methods systematic reviews using JBI SUMARI. This will involve separate quantitative and qualitative synthesis followed by integration of the resultant quantitative evidence and qualitative evidence.

Quantitative synthesis

Data will, where possible, be pooled with statistical meta-analysis using JBI SUMARI. Effect sizes will be expressed as either odds ratios (for dichotomous data) or weighted (or standardized) final post-intervention mean differences (for continuous data)

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and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard chi squared and I^2 tests. Statistical analyses will be performed using random or fixed effects depending on whether heterogeneity is observed or not.[26] Subgroup (e.g. neonatal versus pediatric findings, individual outcomes) and sensitivity analyses will be conducted to explore potential causes of heterogeneity. Where statistical pooling is not possible, the findings will be presented in narrative form including tables and figures to aid in data presentation, where appropriate. A funnel plot will be generated using Stata IC 15 to assess publication bias if there are 10 or more studies included in a meta-analysis. Statistical tests for funnel plot asymmetry (Egger test, Begg test, Harbord test) will be performed, where appropriate.

Qualitative synthesis

Qualitative research findings will, where possible, be pooled using the JBI SUMARI meta-aggregation approach.[27] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings based on similarity in meaning. These categories will then be subjected to a synthesis to produce a comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

Integration of quantitative evidence and qualitative evidence

The findings of each single method synthesis included in this review will then be configured according to the JBI methodology for mixed methods systematic reviews.[23] This will involve quantitative evidence and qualitative evidence being juxtaposed and organized into a line of argument to produce an overall configured analysis. Where configuration is not possible, the findings will be presented in narrative form. The integrated analysis will be used to develop recommendations for research and clinical practice.

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Appendix I: Search strategy

MEDLINE (Ovid) search strategy

(Exp Intensive Care Units, Pediatric/ OR Exp Intensive Care, neonatal/ OR (((Pediatric OR paediatric OR neonatal OR newborn or baby) ADJ5 (“intensive care” OR ICU)) OR PICU OR NICU OR PCICU).ab,ti,kf. OR (exp Intensive Care Units/ AND (“Adolescent”/ OR exp “Child”/ OR exp “Infant”/ OR Adolescent, Hospitalized/ OR Child, Hospitalized/ OR exp “Pediatrics”/ OR (prepube* OR preadolescen* OR adolescen* OR teenager* OR child* OR kid OR kids OR baby OR babies OR infant OR infants OR pediatric OR pediatrics OR newborn* OR neonat*).ab,ti,kf.))) AND (exp Family/ed,th OR exp Family health/ed OR ((exp Family/ OR (father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR Gestational Carrier* OR caregiver* OR carer* OR careprovider* OR caretaker* OR significant other* OR legal guardian*).ab,ti,kf.) AND (Nursing process/ OR counseling/ OR exp “Psychotherapy”/ OR Self-Help Groups/ OR Peer Group/ OR Health Education/)) OR ((father* OR mother* OR families OR family OR familial OR relatives OR parent OR parents OR parental OR parenthood OR stepparent* OR stepfamily OR stepfamilies OR kinship* OR Surrogate* OR sibling* OR brother* OR sister* OR caregiver* OR carer* OR careprovider* OR caretaker* OR significant other* OR legal guardian*) ADJ6 (Program* OR Workshop* OR involvement OR empowerment OR engagement OR communication OR participation OR partnership OR presence OR training OR collaboration OR Teach* OR Intervention* OR counsel* OR education*)).ab,ti,kf.)

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