

The Perceptions and Experiences of Parents and Families of Preterm Infants Who Participate in Family Integrated Care Programs in Neonatal Intensive Care Units: A Qualitative Systematic Review Protocol

Rebecca Anne Carman (✉ r.carman@ecu.edu.au)

Edith Cowan University - Joondalup Campus: Edith Cowan University

Claire Adams

Edith Cowan University

Mary Sharp

University of Western Australia Medical School

Daniel McAullay

Edith Cowan University

Rhonda Marriott

Murdoch University

Jocelyn Jones

Curtin University

Natalie Strobel

Edith Cowan University

Protocol

Keywords: Family Integrated Care, Neonatal Intensive Care Unit, NICU, preterm infants, experiences, perceptions, parents, families

Posted Date: May 18th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-509989/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Background

The premature birth of an infant coupled with admission to a Neonatal Intensive Care Unit (NICU) can pose complex psychosocial challenges to parents and the family unit. Measures designed to counteract the effects of restricted visitation and prolonged separation from the infant within the NICU setting have led to the development of the Family Integrated Care model; emphasis in this program is placed on the active participation of the parent alongside the healthcare team in providing direct care to the preterm infant. The aim of this systematic review is to explore the perceptions and experiences of parents and families of preterm infants who have used a Family Integrated Care program during hospitalisation in a NICU.

Methods

A systematic literature search will be performed on six electronic databases (Medline, CINAHL, Embase, PsycINFO, Web of Science, and Scopus) to identify relevant articles which meet the a priori inclusion criteria. A hand-search of the reference lists of all articles taken to full text review will supplement the search. The search will be limited to peer-reviewed, primary research articles written in English only; no publication date restrictions will be applied. Two independent reviewers will screen all retrieved articles, perform the full-text review, critically appraise the included articles, and extract the data. Where consensus cannot be reached, a third reviewer will be consulted. To assess the quality of included studies and the risk of bias, the Critical Appraisal Skills Programme checklist will be used. Data will be extracted using a data extraction tool developed by the review team and piloted for use by two independent reviewers. A thematic analysis and narrative synthesis of the review findings will follow.

Discussion

This review will importantly describe the experiences of parents and families of preterm infants using a Family Integrated Care program delivered within a NICU; review findings will be used to inform the associated program protocols in a Perth (Western Australia) based NICU and be disseminated via a peer-reviewed publication.

Systematic review registration: PROSPERO, Submission ID: 243818.

Background

The clinical care of the preterm infant in Neonatal Intensive Care Units (NICUs) has historically been provided by medical, nursing, and allied healthcare providers (1). Whilst this specialised care has provided a structured approach which aligns with advancements in technology, the intensity of the NICU environment and the acuity of the infant, coupled with restricted visitation, prolonged separation and minimal physical contact, has resulted in a broad range of poor health outcomes for parents. For

example, delayed infant attachment and bonding, high parental stress, and an increased risk of postnatal depression and post-traumatic stress disorder (1–4). From a mother's perspective, the premature delivery and loss of the third trimester can be emotionally traumatic and physically challenging; their role following the preterm birth is often ill-defined which can potentiate a degree of vulnerability and isolation as they navigate the hospital system. For the preterm infant, the impact can also be significant with evidence of behavioural issues, disability, neurodevelopmental delays, inadequate or variable weight gain, higher rates of nosocomial infection and increased rates of hospital re-admission often observed (1, 2, 5).

In the 1970s, measures designed to advance the clinical outcomes of NICU standard practice provided to preterm infants were first observed in Tallinn, Estonia (6). In this revolutionary model, all non-technical infant care was performed by mothers. These guiding principles have led to the development of the Family Integrated Care program (FICare) which acknowledges the significant and critical contributions of parents in improving the health outcomes of the preterm infant (1, 2, 7, 8). The integration of parents into the direct care of the preterm infant is broadly based on a shared-care philosophy where parents are viewed as active partners with the healthcare team; emphasis is placed on the physical interactions that occur between the parent and infant, and the relationships formed between the healthcare team and parents (8). To support parents and family members throughout the preterm infant hospitalisation and in preparation for hospital discharge, clinical staff provide ongoing education within a safe environment to enable a successful role transition to that of primary caregiver following hospital discharge (2, 3, 8). Stelwagen et al. (4) described the ability of parents to develop the skills required to care for the preterm infant following discharge, confidence and control in influencing the health outcomes of the infant and having insight into the infant's condition as critical factors of FICare program success. Conversely, where self-efficacy was challenged due to power struggles between parents and staff, participants felt that this considerably impacted their confidence.

An alternate model often delivered in the NICU is the Family Centred Care (FCC) program. The FCC program (6, 7) has subtle differences to FICare, which are mostly seen in the degree to which parents are actively involved in providing direct care to the infant; the FICare program requiring more direct involvement. FCC programs are also not conceptually well understood in terms of how the parents are embedded into the care protocols (6, 7, 9). With this understanding, our review will only consider literature that describes the involvement of parents or family members who have participated in a NICU FICare program only, and not FCC.

A review of the published literature based on NICU FICare programs revealed that most studies were observational or randomised controlled trials (RCTs) that focussed on improving the health outcomes of the infant (1, 2, 8). Commonly reported outcome measures in these studies included NICU length of stay (LOS), rate of hospital re-admission, infant weight gain and duration of breastfeeding. From a qualitative perspective, there has been a few studies that have narratively described the experiences of parents and families of preterm infants who have participated in FICare programs (1, 2).

A preliminary search of PROSPERO registered protocols was conducted on 19 March 2021 to determine the extent of work undertaken in the proposed review area. Broad search terms were used to identify systematic review protocols of similar content. The search revealed six registered review protocols which were examined for similarity. However, none were found to be comparable to our proposal or based on a qualitative interpretation of perceptions and experiences. All review protocols identified in PROSPERO reported quantitative measures only to determine and synthesise outcome findings, and two protocols excluded qualitative studies from the search. The Cochrane library was also examined on 25 March 2021. The search terms used to review work undertaken in this area were, '*Family Integrated Care in NICU*'. The search did not retrieve any registered Cochrane reviews, but 31 trials. A screening of the trials via title only, identified one article which required further exploration. However, this item was not a published systematic review or protocol. Following a comprehensive review of PROSPERO and the Cochrane Library, the originality of our proposed qualitative systematic review was confirmed.

The overall aim of the proposed review is to explore the experiences of parents and families of preterm infants participating in a FICare program delivered in a NICU. The review has three primary objectives:

- To explore the perceptions and experiences of parents and families of preterm infants who are participating in a FICare program delivered in a NICU;
- To describe the facilitators and barriers experienced by parents and families of preterm infants participating in a NICU FICare program; and
- To appraise and synthesise qualitative findings to better understand where improvements to program protocols could potentially be made.

Review Question

What are the perceptions and experiences of parents and families of preterm infants who participate in Family Integrated Care Programs in Neonatal Intensive Care Units?

Methods

This systematic review protocol was submitted for registration with the International Prospective Register of Systematic Reviews (PROSPERO submission ID # 243818) and will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P) statement (see checklist in Appendix 1) (10). A PRISMA flow diagram will display the total articles retrieved throughout each stage of the review, describe reasons for exclusion and document total articles submitted for final data extraction.

Study design

The current review will consider studies that feature qualitative evidence only and include, but not limited to, qualitative and mixed methods research, focus groups, phenomenological studies, ethnography, and

grounded theory research.

Participants

There will be no restrictions applied to the age, ethnicity, or gender of participants. The participants should meet the a priori inclusion criteria: parents, families, guardians or caregivers of a preterm infant who have used or are participating in a NICU FICare program. Within the description of the families, siblings, grandparents and aunts and uncles will also be included. For the purposes of this review, a preterm infant is classified as a being born < 37 weeks of age. As the FICare program is typically offered to all infants in a NICU setting, we will include studies that report that at least 50% of the infants included in the study, are preterm infants.

Phenomena of interest

This review will consider studies that explore the perceptions and experiences of parents and families of preterm infants who are participating in a NICU FICare program. We will include studies where the authors have defined the NICU program they deliver as FICare. Studies will be excluded if they have investigated the perceptions and experiences of families participating in an FCC program or any other NICU integrated model of care, which is not described as being FICare.

Search strategy

A systematic search strategy using a three-stage approach will be undertaken using the SPIDER tool framework for qualitative evidence (sample, phenomenon of interest, design, evaluation, research type) (11). Following the identification of key concepts and relevant search terms, a review of google scholar and the use of an online thesaurus will be performed to identify commonly used terms and synonyms. Boolean operators, specific filters (English only and peer-reviewed articles) and truncation for terms and phrases will then applied to enhance the search strategy. Specific Medical Subject Headings (MeSH), index terms and controlled vocabulary will be applied to six individual bibliographic databases: Medline (Ovid), CINAHL (EBSCOhost), Embase (Ovid), PsychInfo (EBSCOhost), Web of Science, and Scopus (Elsevier). No publication date restrictions will be applied, and articles written in English only will be accepted. To supplement the review, a manual hand-search will also be performed on the reference lists of all articles included in the full text review (Stage 3). A draft search strategy for Medline is provided in Appendix 2.

Screening of studies

Following the electronic database search, all retrieved articles will be imported into the online data manager system Covidence, and duplicates removed (12). The titles and abstracts will be screened by two independent reviewers. Articles will be excluded if they do not meet the a priori study design criteria, do not include preterm infants in a NICU setting or if the study intervention is not described as FICare. If there is uncertainty about the intervention used, a full-text review will be conducted. Where resolution cannot be reached concerning article inclusion following title/abstract review, consultation with a third more senior reviewer will occur.

All articles meeting the inclusion criteria will be submitted for full-text review. These will be screened by two independent reviewers and reasons for exclusion of full-text studies presented in a PRISMA flow diagram. For studies where disagreement occurs, discussions will be conducted between the two reviewers until consensus is reached. Where consensus cannot be reached, consultation with a more senior third reviewer will take place to adjudicate a final decision.

Data extraction

A standardised data extraction tool will be developed by the review team and piloted for use by two independent reviewers for all eligible studies. The data to be extracted from each of the included studies will include: study title, first author, year of publication, country of origin, study design, sample size, sample demographics, setting, data collection methods, documentation of the FICare program used, and key findings including experiences, perceptions, barriers and facilitators.

If additional content data is available, we will consider qualitative findings based on groups of people who experience higher than average preterm births. These may be classified by socioeconomic factors, Indigenous status, low- and middle-income countries, and mothers who have increased risk factors (e.g. high alcohol or other drug use) or mental health concerns.

Quality appraisal

To assess the quality of study findings, assess the risk of bias and critically appraise each eligible study article, the Critical Appraisal Skills Programme (CASP) checklist (13) will be used by two independent reviewers. Where disagreement occurs in the appraisal, discussions will be conducted between the two reviewers; a third more experienced reviewer will be used to reach consensus for cases where resolution cannot be achieved. The findings of the critical appraisal will be presented in table format.

Data analysis and synthesis

The research articles taken to full text review will be imported into NVivo for data management and to provide structure during the analysis (14). A six-stage thematic analysis of all data will then be performed by two reviewers (15, 16). Thematic analysis is a useful iterative method for contextual research questions to provide interpretation of explicit and discreet data identified in primary healthcare research (15, 16). The development of key concepts and themes which arise from the analysis will be mapped to graphically display the interactions and associations of each theme; a narrative synthesis of data to present study findings will then follow.

The synthesis of qualitative data will be supported by extracted quotes to provide a descriptive summary of the included studies. A summary of the qualitative findings will also be presented in table format. Although the thematic analysis will be performed by two reviewers, discussions between all members of the review team will occur to reach consensus about the preliminary coding of data and the development of the overarching key themes.

Discussion

For parents, families and main caregivers of infants who are born prematurely, the NICU environment can be a source of high stress and anxiety (1, 2, 5, 8). Prolonged separation, ill-defined roles, and limited direct contact between infant and parent serving to compound a range of health outcomes observed in this setting. This review of qualitative studies will aim to identify the facilitators and barriers associated with FICare programs and importantly attempt to address FICare program utility from the experiences of parents and family members. Review findings will serve to inform and influence current and future NICU FICare programs in the review location (Perth, Western Australia) and importantly contribute to hospital quality improvement.

Abbreviations

CASP: Critical Appraisal Skills Programme

ECU: Edith Cowan University

FICare: Family Integrated Care

HREC: Human Research Ethics Committee

MeSH: Medical Subject Headings

NS: Natalie Strobel

NICU: Neonatal Intensive Care Unit

PRISMA-P: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols

PROSPERO: International Prospective Register of Systematic Reviews

RC: Rebecca Carman

RCT: Randomised Control Trial

Declarations

Ethics approval

Ethical approval for this systematic review has been waived by Edith Cowan University (ECU) Human Research Ethics Committee (HREC).

Consent for publication

Not applicable

Availability of data and materials

The data set supporting the results of this review will be included within the paper and its additional files.

Competing interests

The reviewers advise that they have no conflict of interest in conducting this systematic review

Funding

Funding for this work has been provided by the Women's and Infant Research Foundation. The funder has no role in the development of this protocol.

Authors' contribution

The protocol was drafted by RC. NS provided important conceptual and methods feedback. All remaining authors have read and provided edits to the content. All authors have approved the final version and provide consent for the publication.

References

1. Cheng C, Franck LS, Ye XY, Hutchinson SA, Lee SK. Evaluating the effect of Family Integrated Care on maternal stress and anxiety in neonatal intensive care units. *Journal of Reproductive and Infant Psychology*. 2021;39(2):166-79.
2. Lee SK, O'Brien KM-ICRCMSHTONC. Family integrated care: Changing the NICU culture to improve whole-family health. *Journal of Neonatal Nursing*. 2018;24(1):1-3.
3. Patel N, Ballantyne A, Bowker G, Weightman J, Weightman S. Family Integrated Care: changing the culture in the neonatal unit. *Archives of Disease in Childhood*. 2018;103(5):415.
4. Stelwagen M, van Kempen A, Westmaas A, Vet E, Scheele F. Parents' Experiences With a Model of Integrated Maternity and Neonatal Care Designed to Empower Parents. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN*. 2021;50(2):181-92.
5. Kirby J, McKeon-Carter R. Family integrated care; A Florence Nightingale Foundation scholarship and international journey of discovery for improvement in neonatal care. A review of services. *Journal of Neonatal Nursing*. 2018;24(5):253-6.
6. Levin A, Chalmers B. Family-centered neonatal intensive care. *Birth (Berkeley, Calif)*. 2014;41(3):300.
7. Franck LS, O'Brien K. The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth defects research*. 2019;111(15):1044-59.
8. Franck LS, Waddington C, O'Brien KDoPUoTAUATOMGXC. Family Integrated Care for Preterm Infants. *Critical Care Nursing Clinics of North America*. 2020;32(2):149-65.
9. Ding X, Zhu L, Zhang R, Wang L, Wang TT, Latour JM. Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: A systematic review and meta-analysis of randomised controlled trials. *Australian critical care : official journal of the Confederation of Australian Critical Care Nurses*. 2019;32(1):63-75.

10. Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ*. 2015;349(jan02 1):g7647.
11. Abigail MM, Stephen C, Carolyn C-G, Rosalind M, Sudeh C-S. PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Services Research* [Internet]. 2014; 14(1):[579 p.].
12. Rachel C. Covidence and Rayyan. *Journal of the Canadian Health Libraries Association* [Internet]. 2016; 37.
13. Long HA, French DP, Brooks JM. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*. 2020;1(1):31-42.
14. Jackson K, Bazeley P. Qualitative data analysis with NVivo. 3rd edition. ed. London :: Sage Publications; 2019.
15. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101.
16. Virginia B, Victoria C. What can “thematic analysis” offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health & Well-Being* [Internet]. 2014; 9(0):[1-2 pp.].

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix1and2.docx](#)