Parents’ experiences of transition when their infants are discharged from the Neonatal Intensive Care Unit: a systematic review protocol

Hanne Aagaard1,2
Lisbeth Uhrenfeldt2,5
Mette Spliid Ludvigsen2,4
Liv Fegran2,3

1 Department of Pediatrics, Aarhus University Hospital, Denmark
2 Danish Center of Systematic Synthesis in Nursing: an Affiliate Center of the Joanna Briggs Institute; The Center of Clinical Guidelines – Clearing House, Aalborg University Denmark
3 Faculty of Health and Sport Sciences, University of Agder, Kristiansand, Norway
4 Clinical Research Unit, Randers Regional Hospital, Denmark
5 Department of Health Science and Technology, Aalborg University, Denmark

Corresponding author:
Hanne Aagaard
hanne.aagaard@Skejby.rm.dk

Review question/objective
The objective of this review is to identify, appraise and synthesize the best available studies exploring parents’ experiences of transition when their infants are discharged from the Neonatal Intensive Care Unit (NICU).

The review questions are:
1. How do parents describe their preparedness for bringing their infant(s) home?
2. How do the parents experience the event of discharge?
3. What issues do the parents describe as influencing their transition experiences when the infant is discharged from a NICU to home?

Background
Giving birth to a premature or sick infant is a stressful event for parents.1-3 The parents’ presence and participation in the care of the infant is fundamental to reduce this stress and to provide optimal care for both the premature or sick infant and family.4 A full term pregnancy is estimated to last between 37 and 40 weeks. Preterm infants born before 28th week (5.1%) are defined as extremely preterm, while those who are born between 28th to 31st weeks (10.3%) are defined as very preterm. The majority of the preterm (84.1%) are born between 32nd to 37th week and may have significant medical problems requiring prolonged hospitalization.5

The prevalence of preterm birth is increasing worldwide.6,7 More than one in ten babies are born preterm annually. This is equal to 15 million preterm infants born globally and the second largest direct cause of deaths in children below five.6,8 The highest rates of preterm birth are in Sub-Saharan Africa and South
Asia (more than 60%) and the lowest rates are in Northern Africa, Western Asia, Latin America and the Caribbean. The preterm birth rates in the developing countries vary widely and follow a different pattern than in high income countries.\(^5\)

The preterm birth rate has increased between 1990 and 2010 with an average of 0.8% annually in almost all countries.\(^6\) Morbidity among critically ill newborn and preterm infants vary widely from no late effects to severe complications, such as visual or hearing impairment, chronic lung disease, growth failure in infancy and specific learning impairments, dyslexia and reduced academic achievement.\(^5\) Full term infants may also experience significant health problems requiring neonatal intensive care. The most common reasons for a full term infant to be admitted to a NICU after birth are temperature instability, hypoglycemia, respiratory distress, hyperbilirubinemia and neonatal mortality.\(^9\) Admission of a full term newborn infant from home within the first four weeks after birth is due to jaundice, dehydration, respiratory complications, feeding difficulties, urinary tract infection, diarrhea and meningitis.\(^10,11\)

In the last two to three decades, technological advances in neonatology have improved the survival rates of critically ill and preterm infants.

Two major issues have influenced the design of the NICU wards: i) the increased volume of preterm infants with extremely low gestational age who need neonatology assistance\(^12\); and ii) the impact of the parents’ presence in the NICU to support the infant’s development.\(^13\)

The health status of preterm babies can have a significant impact on the family wellbeing and function. The separation between the preterm infant and the parents is a threat to the attachment and bonding process.\(^14,15\) Worldwide, there has been a paradigm shift in the NICUs over the last decade, inviting parents to be admitted together with the infant or at least to spend most of the day together with their critical ill and preterm infant in the NICU. Parental involvement increases the performing of Kangaroo Mother Care during the admission in the NICU and increases parental preparedness for discharge to home.\(^16\) This change prepares the parents to take over tasks such as nurturing and feeding. The parents are the most important caregivers for the infant during the admission in the NICU and their co-admission increases the bonding and prepare the parents for the transition discharged to home.\(^17\)

Family centered care (FCC) based on a partnership between families and professionals is described as essential in current research on neonatal care. Family centered care is facilitated by parental involvement, communication based on mutuality and respect, and unrestricted parental presence in the NICU.\(^18\) According to Mikkelsen and Frederiksen\(^19\), the central attribute of FCC is partnership with the core value of mutuality and common goals.

A NICU is a high-tech setting where highly specialized professionals care for premature or critically ill infants. During the infants’ hospitalization, the relationship between parents and nurses evolves through an interchange of roles and responsibilities.\(^20\) However, this collaboration is challenging due to a discrepancy between parents’ and nurses’ expectations of their roles.\(^20-22\)

To facilitate parents’ skin-to-skin contact and involvement in their infant’s care, NICUs are now redesigned to facilitate parents’ “24-hour” presence, also called “rooming-in”.\(^14,17\) Seporo et al. describes several benefits with “rooming-in” the NICUs.\(^23\) Staying in the same room increases infants’ and parents’ possibility for “skin-to-skin care”. This improves the infant’s sleep time and temperature regulation, decreased crying and need for oxygen, increases parental confidence and positive infant-parent interaction.\(^23\) Parents’
experience of “skin-to-skin care” and “rooming in” may help parents to be acquainted with their infant and thus prepare for the transition to home. However, despite these positive effects of rooming-in, some negative effects, e.g. less sleep and lack of privacy, have been described by parents who have stayed with their child in a pediatric unit.²⁴

The hospitalization may challenge the normal attachment process and parents’ confidence as caregivers; parents’ preparation for bringing the infant home is thus essential.⁴ The infant’s discharge from the NICU is experienced as a moment of mixed feelings. Going home is a happy event, but at the same time it is combined with parental anxiety.⁴,²⁰ Parents’ pervasive uncertainty, medical concerns and adjustment to the new parental and partner-adjustment role are common concerns.²⁵ To make parents confident and prepared for taking their infant home tailored information, guidance and hands-on experience caring for their infant before discharge is crucial.²⁶,²⁷

During the literature research we became aware of a systematic narrative review protocol by Parascandolo et al.’s concerning nurses’, midwives’, doctors’ and parents’ experiences of the preterm infants’ discharge to home.²⁷ The aim of our comprehensive review is to perform a metasynthesis on parents’ perspectives and their experiences of transition from discharge from NICU to home. We will include qualitative primary studies to offer a deeper understanding of the parent perspective.

**Keywords**

discharge to home; NICU; parents experiences; preparation; premature; systematic review protocol; transition

**Inclusion criteria**

**Types of participants**

This review will consider studies that include mothers, fathers, step-parents or foster parents of infants who are hospitalized in a neonatal intensive care unit regardless of civil status, ethnicity or country of origin.

**Types of intervention(s)/phenomena of interest**

This review will include studies that investigate how parents experience the discharge of their infant from the Neonatal Intensive Care Unit. The included studies should describe parents’ experiences of being prepared for the discharge and the event of the discharge.

Transition in this study is defined as: “a passage from one fairly stable state to another fairly stable state and it is a process triggered by a change”.²⁸ The focus of this review is infants’ discharge from the NICU.

**Context**

The context of this review is a Neonatal Intensive Care Unit defined as an intensive care unit of ill or premature and/or newborn infants. This review includes studies from all four classified levels for NICU care: basic care (level I), specialty care (level II), and subspecialty intensive care (level III and, level IV).²⁹
Types of studies

This review will consider studies presenting qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Search strategy

The search strategy aims to identify both published and unpublished studies and a three-step search strategy will be used. An initial limited search in MEDLINE and CINAHL databases will be undertaken followed by an analysis of the words contained in the title and abstract, and of the index terms used to describe the article.

Initial keywords (with truncation):


Context: intensive care units*, neonatal*, neonatal intensive care unit*, NICU* AND patient discharge*, discharge to home*, going home*, early discharge*, patient discharge*

A second search using all identified keywords and index terms will then be undertaken across all included databases as a part of the review. Databases to be searched at this stage will include PubMed, Mednar, CINAHL, The Central Cochrane Database, ProQuest, EMBASE, ISI Web of Science, Scopus and PsycINFO.

Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Finally all identified research reports will be subject to forward citation searches to reach a complete inclusion of studies to the widest extent possible.

Studies in English, Danish, Swedish and Norwegian languages published between January 2000 and 31 December 2014 will be considered for inclusion. To reflect the advances in medical and technical development and changed parental role during the last decade, the present time frame for the literature search is limited to the last 15 years.

Our aim is to include studies focusing on the preparedness for and the event of discharge from the NICU. The event of discharge is understood as issues in connection with discharge influencing parents' role as caretakers after discharge, such as responsibility, confidence as caretakers or quality of information.

The search for unpublished studies will include Google Scholar, Mednar and ProQuest Dissertations and Theses.

Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to 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 VI). 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. Where textual pooling is not possible the findings will be presented in narrative form.

Conflicts of interest

The authors declare that there are no conflicts of interest.

Acknowledgements

The authors would like to thank Kirsten Jensen, Librarian, Aarhus University, Denmark, for her contribution in preparing and conducting the preliminary literature searches.
References


Appendix I: Appraisal instruments

QARI appraisal instrument

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

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<td>8. Are participants, and their voices, adequately represented?</td>
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<td>10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal: [ ] Include [ ] Exclude [ ] Seek further info. [ ]

Comments (Including reason for exclusion)

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Appendix II: Data extraction instruments

QARI data extraction instrument

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer __________________________ Date __________________________

Author __________________________ Year __________________________

Journal __________________________ Record Number __________________________

**Study Description**

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes □ No □
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Extraction of findings complete  Yes ☐ No ☐