

## Sigma's 30th International Nursing Research Congress

### Neonatal Intensive Care Unit to Home Transition for Families of Preterm Infants

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#### **Purpose:**

The transition from the neonatal intensive care unit (NICU) to home is difficult for parents who may lack confidence and knowledge, both of which may contribute to adverse outcomes in the early post-discharge period including hospital readmission, unnecessary use of health care resources, and parent stress and anxiety. Researchers have noted that the main concerns parents express on discharge are fear about the baby's condition and lack of self-confidence. Over one third of families report parental anxiety associated with feeding their newly discharged preterm infant, a basic caregiving task that, if not done well, may contribute to feeding dysfunction. Additionally, there is strong evidence of an association between preterm birth and maternal risks of anxiety and depression, which have lasting effects on coping skills, attachment, and parenting. Thus, discharge home from the NICU, although highly anticipated by parents, represents a critical point of vulnerability for parents. Assessment and supportive interventions for families at NICU discharge may reduce parental anxiety, increase parenting competence, and improve infant outcomes post-discharge.

There are a number of NICU discharge programs, mostly focused on physiologic stability and sufficient milk intake. However, there are no well-researched programs for NICU-to home transition. Moreover, authors of a recent literature review recommended that discharge programs include parenting classes, home visits after discharge, and on-going communication with staff at the discharging hospital. However, the desirability of these recommendations or their feasibility or effectiveness have not been assessed.

The aim of this study was to define elements of a transition-to-home program from the perspectives of parents whose child was recently discharged from a NICU, and from both NICU and primary healthcare providers. Our goal was to define, from the perspectives of stakeholders, core elements of a transition-to-home program that includes discharge preparation as well as discharge follow-up to support parents during the critical period surrounding the transition to home. We were particularly interested in the immediate pre-discharge period as that is when parents are most interested in discharge preparation and most anxious about their own knowledge and abilities, and the early post-discharge period, as our own research demonstrated that the first two weeks home are most critical in terms of parents' concerns and heightened vulnerability of the infant.

#### **Methods:**

Descriptive qualitative methods were used to identify content and processes that parents and healthcare providers thought would facilitate a less challenging transition from NICU to home. Parent participants were recruited from a large, mid-western city in the United States. Parents were eligible for inclusion if their child was born at <32 weeks gestation and hospitalized in a Level II or III NICU. Healthcare provider participants were recruited from local NICUs and pediatric practices in the same city. Providers were eligible for inclusion if they had self-declared recent experience working with parents of a newly

discharged preterm infant. Data were collected by interviews, which were audiotaped. Tapes were transcribed and analyzed using content analysis; two members of the research team completed the analysis and agreed on the thematic codes. All members of the research team reviewed the analysis and provided additional comments about codes.

## **Results:**

Twenty parents and 10 healthcare providers participated. All parent participants were mothers who were mostly White; their mean age was 30 years and their infants' mean birth gestation was 27 weeks. Infants had been at home between 2 weeks to 3 months at the time of the interviews and were on average 3 months old. Provider participants were mostly physicians who had provided care to preterm infants for many years.

Parents reported they did not feel cognitively ready for discharge; they expressed concerns about what they knew at discharge and how they had been "instructed" in caregiving prior to discharge. They also expressed concerns about the number of questions they had about their child's care during the first few days after discharge. Parents reported that these experiences created anxiety and stress. Health care providers reported concerns about what they perceived to be a general lack of discharge preparation or discharge readiness assessment in the NICU. Providers offered suggestions about providing discharge preparation including offering practical, on-going information about caregiving throughout hospitalization and increasing efforts to engage parents in their child's care during hospitalization. Providers perceived that the process of discharge planning, instructions for parents about caregiving, and lack of parental engagement throughout the hospitalization contributed to delayed discharge and problems in the early discharge period.

Parents and providers were consistent in reporting gaps in parental knowledge and understanding following discharge as well as in reporting that these gaps leave parents feeling anxious, placing the infant at risk for adverse outcomes. Gaps clustered around general infant care, infant feeding, and symptoms of illness.

Parents reported struggling with where to get information after discharge, especially if they thought there was a problem and if the perceived problem occurred soon after discharge. Parents and providers differed in their suggestions regarding who parents should contact first with questions arising in the early post-discharge period. Parents reported they would be more comfortable calling the NICU in these instances and specifically talking to nurses or physicians who had provided care to their child during the NICU hospitalization. Providers generally reported that parents should call the healthcare provider who would be providing on-going care for the child. However, there was no agreement about if calls should be made to a NICU follow-up clinic or a primary care provider. Not all primary care provider participants were comfortable with infant problems that arise in the early discharge, especially those associated with infant feeding.

Both parents and providers thought that proactive follow-up from providers in the early post-discharge period could be beneficial. They did not agree on what form early follow-up should take. Most parents did not want to go to a clinic or physician office in the first few days post-discharge. However, participants were not consistent in their thoughts about which might be most beneficial -- a phone call from a provider or a home visit.

## **Conclusion:**

Researchers have demonstrated that parents experience high anxiety before and after the discharge of their preterm infant to home and encounter numerous challenges when providing safe and effective care for their newly discharged infant. Our results are consistent with this body of research. Moreover, the results demonstrate gaps in care as well as opportunities to improve discharge preparation and transition care. We studied the perspectives of major stakeholders, parents and care providers, to identify

knowledge gaps and potential areas of focus for transition-to-home programs. In adult populations, well-designed discharge preparation programs have reduced rates of hospital readmissions and emergency department visits while increasing primary care follow-up and reducing health-care costs. Unfortunately, empirically tested transition programs for preterm infants and their families do not exist. Moreover, guidelines for discharge preparation for preterm infants and families fail to provide a comprehensive transition-to-home plan. Development of a transition plan incorporating discharge preparation and follow-up to support parents as they assume full responsibility for their infant's care during the critical transition-to-home period should be a goal for future research.

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**Title:**

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**Keywords:**

parents, preterm infant and transition

**References:**

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### **Abstract Summary:**

Preterm birth and subsequent hospitalization is a significant worldwide health concern with financial and human costs. The results of this study provide evidence for transition to home programs from both parent and care provider prospective.

### **Content Outline:**

#### I. Introduction

A. Difficulties experienced by parents in the transition from NICU to home

B. Parent perceptions about discharge planning and follow-up

C. Absence of provider "voice" in transition planning

D. Need for transition programs

#### II. Research Strategy and Results

##### A. Research Design

###### 1. Qualitative descriptive

*a. Interviews*

*b) Audio-recorded*

###### 2. Content analysis

*a) Two coders with agreement established by consensus*

*b) All investigator approval*

##### B. Participants

###### 1. Parents

*a) Infant born <32 weeks*

*b) Infant discharged to home in the last 6 months*

2. Providers

*a) NICU or primary care provider*

*b) History of caring for preterm infants and their families*

C. Results

1. Gaps in parents knowledge and skill at discharge

*a) Infant care*

*b) Infant feeding*

*c) Symptoms of illness*

2. Knowing where to get information and help

*a) Parents prefer contact with NICU*

*b) Providers suggest contact with on-going provider*

3. Potential post-discharge support

*a) Visits to provider*

*b) Home visits*

*c) Phone calls*

III. Conclusion

A. Gaps exist in transition care for preterm infants and their families

B. Implications for practice

C. Future research directions

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