Neonatal Intensive Care Unit to Home Study: The Experience of Mothers Post-NICU Discharge in Caring for Infants Dependent on Medical Technology

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Background

- Increased survival of premature and critically ill infants to discharge
- Growing population of Infants discharged dependent on medical technology
  - Feeding tubes, oxygen, tracheostomies, mechanical ventilation
- NICU graduates have been documented to have a high rehospitalization rate, despite most studies excluding the sickest of infants, with 2-weeks - 3 months being the most likely time.
- Gap in knowledge related to immediate post discharge period

Recruitment: Recruitment posts made in online Facebook support groups, & snowball sampling through Facebook & Email. Recruitment is ongoing.

Current Sample

Inclusion: Biological mother age 18 or older, who is the primary caretaker of an infant discharged from the NICU to home dependent on medical technology, and is within 2 years of their discharge date, with access to phone or internet.

Exclusion: No technology dependence or greater than 2 years post discharge, or internet, technology, and is within 2 years of their discharge date, with access to phone or internet.

Methodology

Design: Fundamental Qualitative Description

Research Question: What is the experience of mothers post NICU discharge in caring for infants dependent on medical technology?

Method: Those interested in the study contacted the PI by email, and completed a screening tool to assess inclusion/exclusion criteria. If included, the participant completed a demographic and infant information form, and a 45-60 minute in-depth semi-structured audio-recorded interview.

Interviews were transcribed verbatim for analysis

Analysis

- Inductive qualitative content analysis
- Transcriptions, field notes, and audio material revisited by study PI in-depth, and in-vivo coding process initiated by study PI.
- Codes organized into a code book and then into categories, and reviewed with co-investigator.
- Categories condensed and organized into themes, agreed upon by co-investigator.
- Member checking to occur at data saturation

Results

1) Finding & Working Towards Normalcy:
- Getting to know my baby
- Modifying the home
- Detachment

2) Feeling unsupported & unprepared:
- Loss of NICU support
- Inadequate discharge plan & teaching
- Fight for in home nursing
- Fear, anxiety, NICU PTSD, PPD

3) Overcoming Obstacles:
- Lack of sleep
- Unable to work
- Supportive Spouse
- Seeking support from other NICU moms

Implications

- The need for care coordination in the community
- More discharge preparation and planning for technology dependent infants within the NICU
- More studies needed to address the gap in knowledge of the post-NICU experience of technology dependent infants

Selected References


More discharge preparation and planning for technology dependent infants within the NICU.