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The Experience of Mothers' Post-NICU Discharge in Caring for Infants Dependent on Medical Technology

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Discharge from the Neonatal Intensive Care Unit (NICU) is a momentous and joyous event for families, however, it is also a marking of the next chapter in which parents transition to the primary caretakers of their complex infants at home. Becoming the primary caretaker of a complex infant often involves administering medications, closely monitoring growth and developmental status, transporting their infant to multiple specialty care follow-up visits, and in some cases, the management of medical technology in the home setting such as tracheostomies, mechanical ventilation, oxygen via nasal cannula, and feeding tubes (Toly et al, 2016; Patel et al, 2017). Increased survival of premature and critically ill infants to discharge can largely be attributed to advancements made in the arena of neonatal care over the past decade (Bowles, Jnah, Newberry, Hubbard, & Robertson, 2016; Wade et al., 2008), however, care advancements have led to a growing population of infants with severe cerebral palsy and pulmonary conditions (Purdy & Melwak, 2012) as well as a growing population of infants' whom are dependent on medical technology at discharge (Bowles et al, 2016; Cristea, Carrol, Davis, Swigonski, & Ackerman, 2013; Seferian, Kackore, Rahman, Nassens, & Williams, 2006; Toly et al., 2016). The percentage of infants discharged to home dependent on technology from the NICU has not yet been reported (Toly et al, 2016), and little is known about the errors in homecare and healthcare utilization during the transition from NICU to home for high-risk infants (Patel et al, 2017). Literature on healthcare utilization rates of NICU infants post discharge has consistently documented high rates of rehospitalizations and emergency room visitations (Ray, Escobar, & Lorch, 2010; Smith, Hwang, Dukhovny, Young, & Pursley, 2013; Vohr et al., 2017), particularly within the first three months' post discharge, and the first two weeks at home is denoted as being the most likely time for rehospitalizations (Boykova, 2016; Boykova & Kenner, 2012; Toly et al., 2016). These findings suggest that the transition to home may not always be an easy path for parental caregivers. It is important to note that studies have often excluded the sickest and most complex infants, such as those dependent on medical technology, in their analysis.

The aim of this study is to address this gap in literature and describe the experience of mothers' in caring for an infant dependent on medical technology during the immediate post discharge period from the NICU. A fundamental qualitative descriptive design as described by Sandelowski (2000, 2010) was implemented to conduct in-depth interviews with mothers whom are the primary caretakers of their technology-dependent infants at home. Recruitment is currently in progress via snowball sampling and online recruitment from NICU mother support groups on Facebook. Recruitment will continue until data saturation has occurred, with a goal of approximately ten participants. Participants will complete an audio recorded semi-structured interview over the phone or audio web-conferencing system entitled Zoom, as well as a demographic form about themselves and their infant. Inductive qualitative content analysis will be used to summarize interview data and will result in major themes which describe the mothers' experiences during the immediate post discharge period. Describing the experience of mothers' caring for their technology-dependent infant in the first few weeks' post discharge from the NICU can help healthcare providers to bolster discharge teaching within the NICU, as well as provide insight into potential interventions to increase caregiver support and guidance in the community.

Title:

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Keywords:

Neonatal, Technology-dependence and Transition

References:

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Abstract Summary:

A qualitative descriptive design was implemented to conduct in-depth interviews with mothers about their experience in the immediate post discharge period from the Neonatal Intensive Care Unit when their infant was discharged dependent on medical technology such as oxygen via nasal cannula, feeding tube, tracheostomy or mechanical ventilation.

Content Outline:

Aim: The aim of this study is to describe the experience of mothers' post Neonatal Intensive Care Unit (NICU) discharge in caring for an infant dependent on medical technology during their first few weeks at home. Medical technology includes oxygen through a nasal cannula, feeding tubes, mechanical ventilation, or tracheostomies.

Research Question: What is the experience of mothers' caring for technology-dependent infants in the immediate post discharge period from the NICU?

Design: Fundamental Qualitative Description

Recruitment & Sample: Recruitment is actively in progress via snowball sampling through public and shareable Facebook Posts and emails sent to a variety of personal and professional contacts of the Principal Investigator. Additionally, recruitment postings have been made in an online NICU Mother Support group on Facebook. At present, one interview has been completed. Recruitment will continue until data saturation occurs, with a goal of approximately ten participants.

Inclusion Criteria: Participants must be over the age of 18, the biological mother of their infant, the current primary caretaker of the infant, and have access to phone service or internet to complete the interview. Additionally, their infant must be (or have been) dependent on medical technology at the time of NICU discharge, and within one year of their discharge date. Medical technology includes nasal cannula, mechanical ventilation, feedings tubes, and tracheostomies.

Exclusion Criteria: A participant would be excluded from the study if they are under the age of 18, not the biological mother of the infant, not currently the primary caretaker of the infant, their infant was not discharged from the NICU dependent on technology, their infant is greater than one year post NICU discharge, or their infant was a twin or other multiple birth.

Methods:

Following approval from the University of Delaware's Institutional Review Board, public and shareable Facebook posts for recruitment were posted both on the principal investigators personal account, and on a separate Facebook account created specifically for the study. Additionally, with the permission and acceptance to an online Facebook NICU mother support group, two recruitment postings were made upon the group wall. Recruitment efforts were also made through snowball emailing with a variety of personal and professional contacts by the principal investigator. From all recruitment methods those who were interested in participating in the study were directed to contact the principal investigator by email, in which they were then instructed to fill out a screening tool to determine their eligibility to participate in the study. If the participant met the inclusion criteria, they were issued an informed consent and demographic information sheet to complete, and scheduled for an audio-recorded semi-structured interview. Participants could choose an interview over the phone, or over an audio web-conferencing system entitled Zoom. Field notes were taken by the principal investigator during the interviews on the semi-structured interview guide. Recruitment for the study is actively in progress, with one interview completed thus far. Two mothers have been excluded from participating due to an infant being a multiple birth, and an infant not requiring technology at discharge. Recruitment will continue until data saturation has been achieved. At data saturation, audio recorded interviews will be transcribed into a word document, and audio material will be deleted per protocol following transcription and analysis. The preliminary analysis results will be shared with the participants via email for the purpose of member-checking, in which their feedback will be encouraged.

Analysis: Qualitative content analysis will be used to generate a descriptive summary of the interview data. Codes will be systematically applied to the data, are generated from the data themselves, and will result in major themes and commonalities among participants that describe their post NICU discharge experience. The inductive method of qualitative content analysis will be implemented, in which categories or concepts will be created from the raw data without a theory based categorization matrix. Ultimately, a descriptive summary will be created in a manner that best represents the data

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