Homeward Bound: The Discharge of a Technology-Dependent Infant from the NICU

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Abstract:

Purpose*: An estimated 3.1% of infants discharged from the NICU require ongoing life-saving medical technological equipment such as supplemental oxygen and feeding tubes. The study purpose was to examine mothers' psychological well-being (e.g., presence of depressive symptoms, posttraumatic stress disorder symptoms) during the three months following their technology-dependent infant's discharge from the NICU.*
Methods: A longitudinal, descriptive study design was employed to examine maternal psychological well-being a three time points; 2-3 weeks prior to discharge, one and three months post-discharge. Convenience sampling was used to recruit 19 mothers of infants dependent on medical technology being discharged from a large Midwest Level 4 NICU in the United States.
Results*: The total scores for maternal depressive symptoms and posttraumatic stress disorder (PTSD) symptoms indicated over one third of the mothers were experiencing psychological distress at discharge. Nearly one half were at increased risk for clinical depression and PTSD and warranted referral for mental health assistance one month post-discharge.*
Conclusions*: A large percentage of study participants reported considerable psychological distress. It is vitally important to perform mental health assessments prior to the discharge of technology-dependent infants prior to discharge and at regular intervals following discharge and refer for mental health assistance as needed. Such finding indicate the critical need to offer enhanced transition services and education as well as assessment of discharge readiness by the interdisciplinary NICU team.*

Introduction

Approximately 450,000 infants are born prior to 37 weeks gestation (1) each year in the United States and are typically admitted to a Neonatal Intensive Care Unit (NICU). In addition, infants with complex medical conditions at birth (i.e., genetic disorders, congenital anomalies) or those who are the product of a high-risk pregnancy (multiple gestation births, maternal diabetes, gestational hypertension) are also admitted to the NICU after birth for stabilization as well as for any necessary surgeries and therapies. Some of these infants will continue to have complex healthcare needs upon hospital discharge, with an estimated 3.1% (2) requiring ongoing support from medical technological equipment, including supplemental oxygen, tracheostomies, mechanical ventilation or feeding tubes. (3-5)

A major gap in the neonatal healthcare literature is the lack of research regarding mothers' level of psychological distress in the first three months following the discharge of their technology-dependent infants from the NICU to home. Prior research indicates that mothers of infants in the NICU, specifically mothers whose infants remain dependent on technology at discharge, are at higher risk for psychological distress, compared to mothers of healthy full-term neonates. (6) This incidence of psychological distress includes higher rates of postpartum depression (7-9) and posttraumatic stress disorder (10-14) than mothers of healthy full-term infants. Technology-dependent infants have a considerably longer average length of hospital stay compared to infants who are not dependent on technology (108.6 days versus 25.7 days) due to the unstable, unpredictable and vacillating nature of the infant's health condition. (2) Thus, it seems likely that mothers of such infants would experience high levels of psychological distress than mothers of infants not requiring such equipment. However, virtually no studies have explored the level of psychological distress experienced by mothers of technology-dependent infants in the first three months following NICU discharge. The purpose of the study was to examine mothers' psychological well-being (e.g., the presence of depressive symptoms, posttraumatic stress disorder symptoms) during the 3-months following their technology-dependent infant's discharge from the NICU so that this knowledge can guide NICU and home-based care of mothers.

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Method

Design

A longitudinal, descriptive study design was used to examine maternal psychological well-being following their technology-dependent infant's NICU discharge. This report of longitudinal data was an unreported part of a larger baseline (pre-discharge) research study described elsewhere. (15)

Participants and Setting

Institutional review board approval was obtained prior to initiation of the study. The study participants were mothers (primary female caregiver) at least 18 years old with an infant being discharged from the NICU dependent on medical technology (e.g., mechanical ventilation, tracheostomy, supplemental oxygen, feeding tubes) that would be required for ≥three months. All maternal participants selected were able to read and speak English. Mothers of children with cancer or a terminal diagnosis were excluded from the study due to the potential for experiencing grief reactions. Convenience sampling was used to recruit participants from a large Midwest Level 4 NICU in the United States.

Instruments

Data were collected using four standardized instruments. An investigator-developed enrollment form was used to record demographic characteristics of mothers, and their technology-dependent infants, including the mother's age, education, partner status, race/ethnicity, and family income plus the infant's gestational age, birth weight, and the total length of NICU stay. The EMR was used to obtain specific information about which the mother was uncertain (e.g., the total length of NICU stay). The type of technology required by the infant was assessed using the Technology Dependency Questionnaire, based on the Office of Technology Assessment's (OTA) rubric for technology dependence. (16,17) The 20-item Center for Epidemiological Studies - Depression Scale

(CES-D) was used to measure maternal depressive symptoms (α =.85).(18) Higher scores indicate more depressive symptoms. Concurrent validity has been supported by clinician's ratings. (18) A total score of ≥16 indicates a high risk of clinical depression. The 14-item Perinatal Posttraumatic Stress Disorder Questionnaire (PPQ) was used to measure posttraumatic stress disorder symptoms (α =.85). This instrument includes questions about symptoms related to childbirth and the postnatal period. (10) Higher scores indicate more posttraumatic stress symptoms. Convergent validity has been established by strong correlations between the PPQ and Impact of Events Scale and the Beck Depression Inventory-II. (10,19) A total score of ≥19 points indicates clinically significant distress that warrants a mental health referral.

Procedures

NICU nursing staff identified potential research participants. Research staff used an IRB pre-approved script to approach eligible mothers. For the initial data collection (Time 1), face-to-face interviews took place in the NICU in a private place of the mother's choosing. (15) All four instruments were administered at that time. At one month (Time 2) and three months (Time 3) following the infant's discharge, mothers were mailed study questionnaires (CES-D, PPQ) plus a self-addressed, stamped envelope to return them to the study office. The technology dependency questionnaire was administered over the telephone. Each participant received a $15 gift card following completion of all study questionnaires at each of the three-time points. A mental health resource sheet was given to mothers who scored ≥ 16 on the CES-D and/or ≥ 19 on the PPQ. Any mother with a CES-D score ≥ 23 was screened for suicide risk with a plan to contact the mobile crisis unit if suicide risk was indicated.

Data Management/Analysis

All data were entered into SPSS and cleaned. Descriptive analyses of study variables were conducted to examine frequencies, distribution, measures of central tendency, and dispersion of scores.

Results

Participants and Demographics

The mothers (N=19) ranged in age from 18 to 41 years (M= 25.63; SD= 6.27). The majority of the mothers had a high school education or less. Approximately one-half of the mothers were African-American. About two-thirds were single, never married. While the household income varied, nearly half earned an income of ≤ $20,000/year. A total of 13 mothers did not follow through with study procedures at various points in time.

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Infants' birth weights ranged from 500 to 3765 grams (M= 1546.1; SD= 1151.8); gestational ages ranged from 23 to 39.29 weeks (M= 29.78; SD= 6.43). The total length of NICU stay ranged from 33.9 to 270.9 days (M= 149.7; SD= 68.7). About one-third of the infants were diagnosed with either respiratory failure or respiratory distress, while another one-third had a primary medical diagnosis of prematurity. At Time 1, a majority of the study infants had a feeding tube (i.e., gastrostomy tube, nasogastric tube) and about

Variable	Time Point	N	Range	*M*	*SD*
Depressive Symptoms	Time 1	19	2-39	14.53	9.90
Depressive Symptoms	Time 2	12	1-41	16.08	11.06
Depressive Symptoms	Time 3	6	1-21	10.33	7.74
Posttraumatic Stress Disorder Symptoms	Time 1	19	2-37	16.53	12.11
Posttraumatic Stress Disorder Symptoms	Time 2	11	2-50	21.18	14.68
Posttraumatic Stress Disorder Symptoms	Time 3	6	1-24	11.33	8.89

Table 1. Descriptive Statistics of Maternal Depressive Symptoms and Posttraumatic Stress Disorder Symptoms Over Time

half required supplemental nasal oxygen, with 15.8% requiring a tracheostomy and 10.5% requiring mechanical ventilation (Table 1). A majority of infants (63.2%; n=12) required one type of technology; 36.8% (n=7) required ≥ two types of technology. Of the seven infants whose mothers responded at Time 2, 42.9% (n=3) required one type of technology, 42.9% (n=3) required ≥ two types of technology and 14.2% (n=1) no longer required technology. Of the nine infants whose mothers responded at Time 3, 33.33% (n=3) required one type of technology, ≥ two types of technology (n=3) or no longer required technology (n=3), respectively.

Total scores for depressive symptoms on the CES-D were ≥ 16 (the cut score indicating an increased risk for clinical depression)18 for 42.1% (n=8), 50% (n=6), 33.33% (n=2) of participants at Time 1, Time 2, and Time 3, respectively (Table 2). The PTSD symptoms scores on the PPQ were ≥19 – a score that is within the clinical range for reported PTSD (10,19) for 36.8% (n=7), 45.5% (n=5), 16.66% (n=1), of participants at Time 1, Time 2, and Time 3 respectively.

Discussion

The goal of this study was to examine maternal psychological well-being for the first three months following their technology-dependent infant's NICU discharge. A large percentage of mothers in this study reported considerable psychological distress that warranted mental health referrals due to high risk for clinical depression and PTSD immediately prior to discharge (Time 1) (15) as well as one month after discharge from the NICU (Time 2). By three months after discharge (Time 3), however, fewer met the threshold of high risk for these two psychological distress conditions.

While past researchers have examined depressive symptoms (8,9,20,21) and posttraumatic stress disorder symptoms (11) in mothers of high-risk preterm infants prior to NICU discharge, none, to our knowledge, have focused specifically on mothers with technology-dependent infants in the first three months following discharge. (22) In one study, 20% of mothers with early preterm infants had scores indicating risk for clinical depression one month after NICU discharge. (23) This is considerably less than our findings of 50% of mothers at the same time point. Interestingly, more of our infants at Time 3 no longer required technological equipment, which may help to explain these findings.

Clinical Implications

Because a high percentage of mothers of technology-dependent infants discharged home had increased depressive symptoms and PTSD symptoms indicating a high risk for clinical depression and PTSD, it is vitally important to perform a mental health assessment of these mothers prior to discharge using the same or similar measures as used in the study on a consistent basis. Both instruments (CES-D, PPQ) are free, in the public domain, and simple to administer within approximately 5-10 minutes. In addition, it is important to perform an assessment of the prior mental health status of mothers before the birth of this infant that includes questions such as previous challenges with depression, use of anti-depressant medications and previous episodes of postpartum depression. (24) For mothers meeting the high-risk threshold, it is imperative to refer them to mental health resources that are accessible, realistic, and affordable. The NICU team can provide crucial assistance to these vulnerable infants and their mothers by developing a list of resources for mental health support for these mothers within the hospital setting as well as community resources for hospital-based support groups, local support groups, and online support groups. (25)

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Mothers with elevated depressive symptoms and PTSD symptoms are particularly vulnerable to the considerable stress that accompanies the teaching and preparation necessary for their

Type of Technological Equipment	Time 1 (N=19)	Time 2 (N=11)	Time 3 (N=9)
Nasogastric Tube	1	0	0
Gastrostomy Tube	14	6	6
Nasal Oxygen	8	1	1
Tracheostomy	3	2	2
Mechanical Ventilation	2	2	1

Table 2. Type of Medical Technological Equipment Used by the Infants Over Time

infant's discharge from the NICU. Therefore, this group of mothers needs enhanced transition services and education as well as an assessment of discharge readiness. The Neonatal Discharge Assessment Tool, developed as a means to conduct a comprehensive assessment of discharge readiness, can be employed by members of the NICU healthcare team especially for mothers of technology-dependent infants who are at high risk for clinical depression and PTSD. (26)

During the first months following their technology-dependent infant's discharge, mothers must learn to integrate care for their infant with their other family and household responsibilities. (22,27,28) Therefore, it is essential that healthcare providers provide the education and support to facilitate the transition home from the NICU as smooth as possible. Preparing a mother to care for a technology-dependent infant at home safely requires education from an interdisciplinary team of healthcare professionals. Because parents (mothers) are an integral partner in this team, parents need to be included in team discussions and any care decisions. Prior research indicates that the most frequently reported source of stress for mothers during the transition of their infant home from the NICU was their lack of involvement in care and decision making. (29) NICU physicians and nurses play a major role in reminding all providers that mothers should be included and their contributions to decision making noted and appreciated.

"As exciting as it is to prepare to take an infant home from the hospital, mothers of technology-dependent infants often find it to be both a daunting and overwhelming task. Structured, organized discharge teaching with return demonstrations from the mother and one other responsible caregiver is a cornerstone of safe discharge. "

As exciting as it is to prepare to take an infant home from the hospital, mothers of technology-dependent infants often find it to be both a daunting and overwhelming task. Structured, organized discharge teaching with return demonstrations from the mother and one other responsible caregiver is a cornerstone of safe discharge. (3) This preparation for discharge can require weeks of coordinated teamwork depending on the amount of technology the infant will require at home. This preparation includes early discharge teaching for medical technological equipment such as a gastrostomy tube with time to practice feeding the infant as well as routine care of the gastrostomy tube and emergency care in the event the tube becomes dislodged. A previous study found that mothers of preterm infants discharged from the NICU were constantly stressed about using gastrostomy technology without the support of the nurses. (30) In addition, mothers require education regarding how to protect the gastrostomy tube from inquisitive infants (and at times siblings). Further, parents need instruction regarding how to manage everyday family life while still safely meeting the technology-dependent infant's feeding needs via the gastrostomy tube (e.g., the timing of feedings, total amount per 24 hours). Another important topic to address with parents is how to talk to other extended family, friends, or community members about the gastrostomy tube. (31)

Ensuring that parents have a simulated home experience in the hospital prior to discharge home is quite important. Prior to discharge, the mother should independently care for the infant in the hospital for 24 hours, a crucial component of discharging a technology-dependent infant to home. This opportunity gives the mother the ability to see her strengths and be re-evaluated in areas in which she has concerns; subsequent restructuring of the mother's educational needs should follow. Further teaching sessions might be required demonstrating that the mother can independently care for the infant prior to discharge.

Limitations

Two limitations of the study were the small sample size and the high rate of subject attrition. In addition, this study did not measure social support or the amount of home nursing that the infant might have received following discharge from the NICU. Future research should include measures of emotional and instrumental support as well as an assessment of prior maternal psychiatric history (e.g., clinical depression, use of anti-depressant or anxiolytic medications, previous episodes of postpartum depression). Testing of specific hospital-based and home-based interventions to reduce maternal depression and PTSD due to caring for technology-dependent infants are avenues for future research.

Conclusion

A high percentage of mothers of technology-dependent infants discharged home from the NICU have elevated depressive and PTSD symptoms indicating an elevated risk for clinical depression and PTSD. It is important to perform a mental health assessment of these mothers several weeks prior to their infant's discharge using the CED-D and PPQ or a comparable assessment tool as well as a discharge readiness assessment. This mental health assessment should also occur during the NICU follow up visits during the first three months post-discharge as mothers adjust to juggling care for the technology-dependent infant and other household and family responsibilities. The NICU team can provide crucial assistance and education regarding community mental health resources for local and online support groups. Mothers bringing home technology-dependent infants from the NICU for the first

time have already faced considerable stress and trauma related to the uncertain and vacillating health state of the infant. NICU physicians and nurses should be sure mothers receive effective assessment, support, and education not only prior to discharge but also during the immediate months that follow.

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