Emotional Experiences of Mothers of Newborns Admitted to the NICU

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ABSTRACT

The transition to parenthood is an emotional life experience. Giving birth to a healthy baby and bringing the child home shortly thereafter is a significant emotional occasion. Even when everything goes as smoothly as possible, parents often deal with various degrees of stress and anxiety. Their lives will never be the same and they will have an entire new set of responsibilities swaddled in a little blanket. Some parents do not experience this transition the way they had envisioned and are forced to spend the first phase of their child's life within the walls of a Neonatal Intensive Care Unit (NICU). Studies have shown that this situation has major emotional implications for parents, both immediate and long-term. The purpose of this study is to describe the self-identified emotional responses of mothers who experienced having a newborn child hospitalized in the NICU immediately following birth.

Emotional Experiences of Mothers of Newborns Admitted to NICU

Parents of Neonatal Intensive Care Unit (NICU) patients often suffer from feelings of stress, depression, anxiety, helplessness, and alienation during their child's stay (Obeidat, Bond & Callister, 2009). Mothers may feel guilt, responsibility, failure, and shame about their infant's hospitalization (Obeidat, et al., 2009). As a result, they have a much more difficult time bonding with their child. Feelings of separation during their child's time in the NICU can lead to emotional distance as their child grows up, and even disturb neurological development of the child (Sweet & Mannix, 2012). According to Busse, Stromgren, Thorngate, and Thomas (2013), parents have a difficult time feeling like 'parents' since they were not the primary caretakers of their newborn children in the critical days immediately after birth.

It is widely understood that having a child in the hospital is an emotionally taxing situation for parents, no matter the circumstances. With that being said, one can imagine how difficult it is for parents who have just given birth to a new child. Many times, the infant is whisked away under the care of NICU staff before the parents are able to respond or internalize the significance of the new addition to their family. The first phase of parenthood for these couples is spent in the confines of a hospital rather than welcoming their baby into their homes. Research has been conducted to identify the stress factors that parents, particularly mothers, deal with while their infant is in the NICU. Other studies have reported on parents' overall experience during their child's hospitalization.

Multiple researchers have concluded that there needs to be interventions in place to minimize or altogether avoid stress and the related emotions that come along with stress. But before an intervention can be developed, it is essential to have a more detailed understanding of what mother's experience emotionally as a result of their infant being in the NICU.

PURPOSE

The purpose of this study is to collect selected mother's accounts of their emotional responses to the experiences of having a newborn child in the NICU to identify descriptions and expressions of mother's emotional experiences as a result of their newborn's hospitalization. The goals of this study are to gain a more in-depth understanding of mother's emotional experiences as a result of their child having been in the NICU, to confirm the emotional experiences that other research projects have identified, and to elucidate more detailed descriptions of these women's experiences. With the confirmation and thorough depiction of mother's emotional recounts during this fragile time in their lives, I will have a better foundation for future research to create interventions to lessen or minimize the emotional strain evidenced in these experiences.

REVIEW OF THE LITERATURE

Parents of infants in the NICU have a variety of stressors to deal with during and after their infant's hospital stay. The feelings of stress, depression, anxiety, and helplessness are the most commonly acknowledged by researchers (Obeidat, et al., 2009). Most researchers agree about the causes of parental stress in this situation and the negative outcomes they produce, both short term and in the long run. They agree that there need to be more interventional measures to lower the stress levels of parents to ease the their minds and better facilitate the parent-child relationship.

Sweet & Mannix (2012) sought to identify the kinds of stress experienced by parents in the NICU. Their sample consisted of parents, over the age of 18, whose babies were in the NICU for at least five days. They concluded that the alteration in the "role of the parent" along with the physical unstable appearance of their child was a main cause for parental stress. Another factor

that leads to parental stress according to this study is the setting of the NICU: the loud, unfamiliar, and busy nature of the hospital. Having a pre-term birth causes enough stress on its own without the following separation of the infant being in a critical unit for a period of time. Between physical separation and the raised levels of anxiety and stress, it is common for the parents to have a more difficult time bonding with their infant.

The main types of stress and anxiety found were separation from the child, especially when the child was in very critical condition, lack of communication with hospital staff, not understanding what was going on, the conduct of the hospital staff, and not being understood by those around them (Sweet & Mannix, 2012). The stress that parents feel during this time does not stop at discharge however, and continues to have negative effects as the child is growing up. This perceived parental stress could affect the parent-child relationship and even the child's neurological development. Although it has been recognized that support, engagement, and understanding are key in lowering stress levels in parents, few hospitals have effectively addressed these issues.

Obeidat and colleagues (2009) following a systematic review of available literature reported on the overall experience of parents in the NICU. They concluded that there needed to be interventions in place to lessen "parental feelings of stress, anxiety, and loss of control" (p. 23). These interventional methods should revolve around supporting development and the family as a whole. Obeidat and colleagues acknowledged that mothers of NICU infants have a higher chance of not bonding as well as mothers of healthy infants, partially due to the mother's anxiety and depression. Mothers feel responsible for their child's condition and feel as though their child will have difficulty developing. These authors cited another study that concluded, "mothers experience feelings of ambivalence, shame, guilt, and failure" (p. 24). Parents experience

distress when their infant is in pain, as they can do nothing personally to help their child. They do not feel like a parent, but rather uneasy, fragile, alienated, hopeless, and useless. Mothers and fathers felt better when they were at their child's bedside, when NICU staff was open in communicating with them about the condition of their child and when they believed they were treated as individuals.

Busse, Stromgren, Thorngate, and Thomas (2013) researched the relationship between how parents responded to the stress of their infant being hospitalized. They had thirty parents complete the Parental Stressor Scale, a well-established self-report survey. This research focused on the stressors of fatigue, anxiety, depression, and sleep. These researchers found that there indeed is a strong correlation between the previously mentioned stressors and parental stress. Parents have a problematic time trying to be 'parents' in the NICU setting, where the real caretakers of their new children are unfamiliar staff members providing direct care to their child in what is perceived as an uncomfortable environment. Mothers were shown to still have substantial stress months after the child had been discharged from the hospital.

Clottey and Dillard (2013) found that many parents suffer from post-traumatic stress disorder (PTSD) as a result of their child being in the NICU. Their PTSD is an outcome of other parent's stories, fear for their child's life, quality of life, and medical events that occur during their child's stay in the NICU. Although not in an actual war environment, parent's PTSD is just as serious as military veterans. Just like war veterans, parents can suffer from reliving the traumas, avoiding the subject all together, and having trouble going about their daily lives. Clottey and Dillard argue that PTSD may be more prevalent among this population than people assume. PTSD can easily go unidentified by the parent while they suffer silently. It is common for parents with PTSD to avoid attachment with their infant to lessen the frequency of traumatic

flashbacks or memories, which causes their relationship with their child to suffer greatly. Clottey and Dillard recommend that health professionals provide parents with acceptance, support, and encouragement to reduce issues from possible PTSD during and after the child's hospitalization.

Murdoch & Franck (2012) identified six major themes as an outcome to a descriptive phenomenological study of mother's experiences after their child was discharged. These themes were apprehension, confidence, responsibility, awareness, normalcy, and perspective. Mothers are apprehensive about the unstable, fragile status of their infant. They become less apprehensive and more confident as their child's health improves. During the course of their child's stay, they develop an awareness of their infant's needs. After a period of time, mothers are able to see their child's stay in a different light. Murdoch and Franck posit that not enough attention has been focused on the transition of parents from being in the NICU setting to being at home.

The findings in these five studies were consistent. While some focused more on identifying parental stress factors, others were centered more on the parents' overall experiences during and after their child's stay in the NICU. Parental stress results from the physical and emotional environment, does not end when they leave the hospital and can have crippling effects later on in life as well. Interventions need to be administered to lessen the stress that parent's suffer from during their child's stay in the NICU. These interventions would lead to improved parent-child relationships, children's neurological development, and an overall better family environment.

Multiple researchers have recommended that interventions be in place to minimize or altogether avoid stress and the related emotions that come along with stress. But before an intervention can be developed, it is essential to have a more detailed understanding of what mothers experience emotionally as a result of their infant being in the NICU. The purpose of this

study will be to gain a more in-depth understanding of mother's emotional experiences as a result of their child having been in the NICU.

DESIGN/METHODS/PROCEDURES

This research employed an extensive semi-structured individual interview process to develop a case study analysis of responses from two participants who met the stated eligibility criteria. Participants were recruited from families whose child was a patient at Austin's First Steps High Risk Follow-up Clinic or via nomination from UT Nursing faculty. Permission was obtained to display brochures in this professional office for mothers of infants who had been in NICU. Flyers were also made available to nursing faculty at UT Austin, with a cover letter so that they are informed about the study to share with any woman they knew, personally or professionally, who met criteria for inclusion.

After being contacted by a potential participant, eligibility was confirmed. Participants were then sent a copy of the informed consent and an interview appointment time was scheduled. During interviews, which lasted around one hour, the consent forms were signed prior to interview and audio recording starting. Participants completed a demographics form before the interview began. When the audiotaped interview was completed, the participant was notified that the recording device was turned off and that the data would be stored securely until destroyed after completion of study. The researcher then transcribed the interviews verbatim and removed all identifiers. Participants were assigned a letter ("A" and "B"). Transcripts were then analyzed to identify recurring terms and phrases or expression discussed.

PARTICIPANT DEMOGRAPHICS

The target population was mothers who had a child admitted to the NICU for more than one week but less than two months anytime from the year 2014 to present. In addition the child

must have been admitted to NICU within 2 days of being born and discharged at least 1 month before the interview. These criteria were developed with the impression that having a child in the NICU for over a week allows the family to enter into some rhythm or schedule and have already had an adjustment period to their situation. It is possible that after an extended amount of time, mothers will get comfortable with the setting and their emotions or how they remember them may become altered. Mothers were excluded from participating if their child has a chronic illness that required additional hospital visits or procedures, if they were hospitalized for an extended period of time after the birth, or if a child, sibling, or significant other had passed away within time of data collection.

The sample of this research study consisted of two married women, in the age range of 38 to 40 years old. Both of their NICU experiences were with their first child, who is to date their only child. They were both able to deliver their child at the same hospital that had the NICU where their child was admitted.

Mrs. A. delivered at 31 weeks and 2 days gestation after a complication-free pregnancy. She experienced Premature Preterm Rupture of the Membranes that precipitated her early labor. Her baby was in the NICU for 35 days following birth. At the time of the interview, her baby was 5 months old.

Mrs. B. delivered at 35 weeks after dealing with preeclampsia. She was hospitalized for a few days after her delivery, while receiving treatment for preeclampsia. Her baby experienced Intra-Uterine Growth Restriction, which caused her to be hospitalized in the NICU for 21 days. At the time of the interview her baby was 11 months old.

FINDINGS

Mrs. A.

Mrs. A.'s primary emotional response to her child's hospitalization in NICU was anxiety.

Mrs. A. stated she was "hugely anxious, all the time… constantly" with "racing thoughts about horrible things that could happen". She also had a sense of helplessness: "My job was very limited- just pump"; "there is nothing you can do for your child". Mrs. A. talked about fear. She simply expressed that "there was this sense of, if this could happen, anything unexpected could happen" which lead her to be very afraid that her baby would die. A longer-term effect of this fear was a suddenly developed fear of flying, which she stated was "totally illogical". Her reasoning was "somebody has to win that lottery, it could be me, I won this one".

Mrs. A. gave examples of what information she and her husband gathered daily, such as when the baby had a bowel movement, how much she had eaten, how she slept, how much she weighed. She stated that she would call the NICU nurses in the middle of the night when she was expressing milk to get more information on her baby. She claimed that this helped reduce her anxiety and fear.

Mrs. A. pointed out that the presence of her and her husband did not seem to make a big difference to their baby. "We'd go and spend an hour or two but I know there are people who just live there. I went back to work. We would swoop in and hold her for a little while, get all the data, take a picture, and then leave, and go on with our lives." Mrs. A. said she felt like slowly added "mom-ness" little by little as her child was getting ready to be discharged.

Mrs. A. said she still is angry with God because she did not feel like she deserved this to happen to her and her baby and wanted to know why it did. Looking back on it though, she realizes that she was able to get through it and it made her a stronger person. Mrs. A. says that she drew her emotional support from other people; she considered the medical staff of the NICU as a "big cloud of comfort and protection".

Mrs. B.

Mrs. B.'s primary emotional response was a feeling of being "out of control" as she was "leaving [her] most vulnerable part behind". "You have no idea what it's like to have to leave your child in the care of another human being". She also conveyed a strong sense of stress. As Mrs. B. pointed out though "To say it was stressful is… there isn't a good enough word that I know to describe how it feels".

Mrs. B. also verbalized feelings of being a failure, "like you failed your child as a mother, the one thing you were supposed to do [have a healthy child], you screwed up." Mrs. B. believed that her fear caused what she called "rebound control". She stated that she felt that this new drive to control was due to feeling like her baby "was going to be taken away". Looking back she sees that the "helplessness and lack of control at the beginning is making me want to control things that are uncontrollable now."

The information the nurses gave Mrs. B. daily was considered essential. Mrs. B. laughingly stated, "I know the exact conversion of grams…All those things became important" Mrs. B. focused on being in the NICU when she was reflecting during the interview. "It's a production: you gotta (sic) show up between these hours, wash your hands, scrub everything down, no germs can't go in, then sit down with your baby, and on good days you get to watch her sleep, hold her for a little bit and then you have to put her back. All the machines kept beeping…"

One coping strategy that Mrs. B. discussed being beneficial was talking to someone who had been in the same situation. She had a friend who recently had a child in the NICU who was able to" validate" her emotions; "she said basically you're not crazy, I felt this way too." Talking with someone helped her to "shift focus on what you perceive to have been loss with a focus on

what you have. The goal was to have a child…. to have a baby that is alive and has the opportunity to thrive and that is what you got."

Mrs. B. felt slightly overwhelmed when her baby was ready to go home, saying that she was so happy when the doctor said her child could be discharged and then thought "Oh no, now I have to take care of her". It seemed as though the daily care that she didn't have to do while her baby was admitted was suddenly going to be all her responsibly and this made her nervous at the beginning. Mrs. B. wanted to find someone to blame for her baby's situation, since she felt that she was "robbed of this [ideal birthing] experience. But since she has had time to move forward since her child's hospitalization she said that she can see that "He carried me through it… you only realize when you look back and you're like there is no way I did this on my own. That was all [God]"

Comparison of Participants

Both participants repeated multiple times that the "only thing" they could do was pump milk for their baby. This perceived helplessness and only limited contributions led to what they identified as "rebound control" and "illogical fear". Anxiety was a chief complaint by both mothers. A sense of fear was a root cause for many of their identified feelings. Both talked about how they clung to every data piece they could get about the child.

Mrs. A. and Mrs. B. had different outlooks on their actual time in the NICU. Mrs. A. did not feel as though she was needed in the care of her child while Mrs. B. discussed the importance and production of seeing her child. Both Mrs. A. and Mrs. B. said that having the one job that only they could do, giving their child the "exact nourishment your child needs" was very important and made them feel useful. Both mothers mentioned how the transition "to being mom" is different from the normal path of delivering a healthy baby and going home with them

after two days. Both described feelings of anger with God although it manifested differently between the two.

ANALYSIS

After extended interviews with the two participants, I was able to understand the varied and intense emotional experiences that these mothers experienced. Both had somewhat similar experiences but experienced events differently emotionally and for different reasons. Each had distinct ways of coping with the intense emotions experienced during and after hospitalization of the child in the NICU.

LIMITATIONS

Several limitations to this research were identified. The small number of participants limits generalizability of findings to other mothers of NICU hospitalized newborns. Several factors resulted in limited participant numbers. The data collection period was limited by student enrollment constraints. Several potential participants were identified but did not meet the eligibility criteria that may have been too constricting. The agency used for recruitment maintains a large practice primarily directed toward extended care of the NICU baby following discharge. Yet, the lack of response from former NICU mothers to participate in an interview concerning their child's stay in the NICU may suggest that they have such a difficult time in the NICU that it is too traumatic to discuss so soon after discharge.

SUGGESTIONS FOR FURTHER RESEARCH

All the previous research reviewed for this study focused on causes and effects of parental stress in the NICU but not on ways to prevent or even lessen these stressors. Some research did propose that hospitals have not done enough to address these issues. There has not

been adequate research on ways to support this population of parents who experience these intense emotions for an extended period of time.

Interventions need to be developed to prevent parents from feeling too stressed while their child is in the hospital. There should also be interventions or assistance to help parents' transition to life with a newly discharged newborn. In order to prevent relationship stress and child developmental complications, new parents need to be better bonded with their infant and feel comfortable before they leave the hospital with the infant.

Researchers are in agreement that further action needs to be taken to lessen feelings of stress, anxiety, and depression Therefore, future research is needed to develop and test active supportive interventions for parents during this period to lessen stress and prepare for the transition to discharge and care at home. New parents have multiple stressors and responsibilities. They do not deserve to have even more put on their shoulders, especially when they already have to deal with their newborn staying in the NICU and when there are solutions waiting to be discovered to alleviate their emotional strain.

Mrs. A. stated that she hoped that this study or further research would "shed light on" the influence of the parents spending time in the NICU. She and her husband did not spend an overwhelming amount of time there because they did not feel like they had any strong need to be there and believed that their child was well taken care of. But she said she knows some people who basically live at the hospital and spend all their time there. She was curious if there were a "better" choice out of the two of them for the baby's outcome, or some middle ground of being present for bonding time and letting the nurses take care of the baby while parents take time to deal with the emotional effects.

After reviewing the previous research, I started to have more insight into the emotions and experiences that families with babies in the NICU have to deal with. However, following the interviews I had, I was able to understand much more deeply what these mothers deal with emotionally, both short and long term. It has given me a unique perspective for my future encounters with families in this situation. I have developed a passion for the patients in this clinical setting that I believe will be beneficial to my future learning. I intend to research this topic more to develop interventions to lessen the negative emotional experiences experienced by mothers of newborns who are admitted to the Neonatal Intensive Care Unit.

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