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**What happens after the NICU?
Parents Experience of Caring for their Premature Infants at Home
Amanda Pignon**

Abstract

This paper reviews the literature on what happens after the NICU with premature babies and their families and provides perspective of a lived experience. There have been numerous studies conducted on the traumatic experience of the NICU, however there is limited research involving the parenting process and experience following the NICU and caring for a high risk infant at home. Articles were searched through two databases, CINAHL and Pubmed, yielding 15 articles in which three specific themes were outlined; psychological distress of parents, perceptions of parents and linking family to resources. While there are programs available for families, not all families are provided access to these programs or other resources. It seems that further research should be conducted on parent's experiences and finding out which services would be helpful after their stay in the NICU.

Keywords: NICU, Parenting, Premature Infants

What happens after the NICU? Parents Experience of Caring for their Premature Infants at Home Amanda Pignon

Prematurity is currently the leading contributor of infant death in the United States (Centers for Disease Control and Prevention, 2015). One out of every ten babies are born premature and prematurity continues to be the leading cause of neurological deficits in children (CDC, 2015). A premature baby is typically admitted to the neonatal intensive care unit (NICU) following birth. Depending on their gestational age babies can spend weeks or months in the hospital with the threat of having long term issues such as intellectual disabilities, cerebral palsy, breathing or respiratory issues, visual problems, loss of hearing, and feeding or digestive issues (CDC, 2015).

Parents undergo a tremendous amount of emotional and physical distress during their child's stay in the NICU. Stress is somewhat alleviated by having a skilled multidisciplinary team that provides around the clock care for their child. Parents have that little bit of comfort knowing that if something were to go wrong, their child is in the best place they can possibly be. There is a vast amount of research concerning the NICU journey and the traumatic experiences that occur during the hospitalization. However the consequences of having a baby born premature linger for a lifetime for both the baby and their family (Stokowski, 2004). This is why looking past the NICU when parents are finally at home for the first time with their premature baby should be considered another popular topic of interest. The statistics alone on developmental outcomes for premature babies can be very anxiety driven for parents. It's not uncommon for parents to exhibit psychological distress following their baby's hospitalization. Due to the possible threat of developmental issues or neurological disabilities, psychological distress can exacerbate and persist at home while caring for a premature baby. It is important that parents are provided the necessary amount of support, education, and available services needed to ensure they are able to properly care for a baby that is consider at risk for hospital readmission, disabilities, and deficits. In this paper I will discuss the literature and relate the literature to my lived experience.

Methodology

A literature review on preparing for the steps after the NICU, stressors that accompany caring for a preterm baby, and programs available for parents were searched and analyzed for the purpose of this scholarly reflection paper. Two databases were utilized in the search; CINAHL and PubMed using the keywords: 'psychological stress after discharge the NICU', 'parent's experience of premature infants', and 'parenting programs for premature babies' yielding a result of 17 articles that were analyzed in the final literature search. Articles that were excluded were articles with parents and babies still in the hospital. Articles that were included were involving families at home with their premature child following the NICU at varying times in the children's early lives. Three specific themes emerged that will be discussed. These included psychological distress of parents, perceptions of parents, and linking families to resources.

The Literature

Psychological distress of parents

Having a premature baby is a significant stressor and challenge to parents (Thomas, Renaud, DePaul 2004; Eiser, Eiser, Mayhew, Gibson, 2005). A premature baby poses a high biological risk, and parent's emotional health become strong indicators of infant developmental

outcomes (Thomas et al., 2004). Mothers need to face that they could be parenting a very sick and disabled child. Infants born with an extremely low birth weight can have multiple health care conditions which result in parenting stress (Zerach, Elsayag, Shefer, & Gabis, 2013). The emotional well-being of the parents starts in the NICU as the discharge date approaches. Mothers were shown to experience an elevation in depression, stress, anxiety, and post-traumatic stress symptoms while in the NICU, that may continue on for months, and even years following discharge from the hospital (Holditch-Davis, Miles, Weaver, Black, Beeper, Thoyre, 2009; Holditch-Davis, Santos, Levy, White-Traut, O'Shea, Geraldo, & David, 2015).

At home parents have to be vigilant and acknowledge that their child has a vulnerability. Additionally, parents have to provide a positive and nurturing environment in which the baby is able to thrive, meet age appropriate milestones, and become independent (Eiser et al., 2005). This can create internal and external stressors for parents. They feel that they are faced with more challenges than they can handle, and their own health and well-being is implicated with the angst their baby's survival (Eiser et al., 2005). Families of very premature babies reported poorer family functioning, and higher family burden compared to families of a full term baby. Parents who had a mental health problem reported even higher parental stress (Treyvaud, Doyle, Lee, Roberts, Cheong, Inder, & Anderson, 2011). Another study looked at the mother's psychological adjustment of their very low birth weight baby in the second half of their first year of life, showing that the biological risk of their child increased parenting distress (Halpern, Brand, & Malone, 2001).

Many factors aside from the child's difficulties can cause internal and external stressors. The results of one study showed the parenting stress was significantly higher in mothers of premature babies compared to full term mothers at one year of age corrected (Gray, Edwards, O'Callaghan, Cuskelly, Gibbons 2013). The mother's symptoms of depression paired with the child's temperament were factors of parenting stress based off a study using the Parenting Stress Index (PSI) tool (2013). The parent's well-being was impacted since they felt that their child was dealing with a higher rate of difficulties and therefore became a form of parenting stress (Eiser et al., 2005).

Caring for a child with vulnerabilities can lead to maternal mental health issues such as Post Traumatic Stress Disorder (PTSD), anxiety and depression. Parental depression was reported the highest during the first three months, and symptoms continued to exist between both mothers and fathers at varying levels during their child's first year of life (Doucette & Pinelli, 2004). Resources along with family functioning declined for mother's and families following the NICU, and at the three-month assessment, which correlated with higher rates of depression at that time period (Doucette & Pinelli, 2004). The psychological distress that parents may exhibit while caring for their premature baby can have effects on the parenting process through the eyes of the parents and how sick their child becomes.

Perceptions of Parents

The day of discharge from the NICU brings mixed feelings for parents. The discharge date is both a joyous and stressful transition to home for families whom are now assuming care for their premature baby who required around the clock care by a skilled multidisciplinary team until that date (Bakewell-Sachs & Gennaro, 2004). Premature babies continue to require some kind of specialized care due to their central nervous system immaturity and higher risk for readmission to the hospital during the first year of life (Bakewell-Sachs & Gennaro, 2004). This can be very concerning for parents and can create undue stress while at home. According to Thomas et al. (2004) parenting distress alters both how competent parents feel and their interactions with the baby. Infant characteristics such as pain, sadness, fear and distress continue on after date of discharge, and has the ability to impact parental perceptions (Raines, 2013).

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Parental perceptions were seen in the literature as to have negative connotations in the child's life. One study suggested that parents adopt a more prevention based parenting style that can ultimately lead to negative implications to the infant's quality of life. This was due to their perceptions about their infant's vulnerability of prematurity (Eiser et al., 2005). Another study suggested that mothers whom are caring for a premature child can have negative impacts on maternal mental health in that they see their child having more difficulties and could provoke even more problems than they actually have (Eiser et al., 2005).

Although these perceptions are sometimes not warranted, parenting a premature baby is considered to be somewhat different to a full term baby according to some research. Premature babies do not respond as predictably, and their responses are organized in a different fashion as compared to full term babies (Bakewell-Sachs & Gennaro, 2004). The care required for a premature baby varies in term of how sick or how much care they need. Caring for a premature baby with a neurodevelopmental disability has shown an increased burden on family finances, planning, and parenting all at once (Treyvaud et al., 2011). The burden that families face could somewhat be alleviated with proper support and adequate resources in the community.

Linking families to resources

Services and supports provided to families following discharge can help with long term stress, anxiety, and coping with a sick or at risk baby. Practitioners need to reassure parents that they are not being left alone after discharge, and clarify issues that are best discussed with the NICU or the new community providers that assume the care following discharge (Garfield, Lee & Kim, 2014). Families who receive information about community providers prior to discharge can facilitate greater engagement in parenting strategies, and early intervention can ease the stress level for parents. A quick postnatal screen by NICU staff can help pinpoint problems or distress that can occur after discharge. Understanding the factors that influence a parent's stress before discharge from the NICU can help nurses develop interventional strategies that address those exact stressors for a smoother transition to home (Raines, 2013). Interventions should facilitate a normal environment with typical interactions between the child and their family and peers (Eiser et al., 2005).

Early intervention (EI) is a program that delivers neurodevelopmental evaluation and therapy as an option after NICU discharge to help with transition to home and with the community (Garcia & Gephart, 2013). These programs have been found to alleviate parental stress with fewer behavioral and regulation problems following the intervention. It is recommended that very premature and very low birth weight babies could benefit from EI services. However, these referrals have the ability to help all babies and their families (Garcia & Gephart).

Creating Opportunities for Parent Empowerment (COPE) is an intervention tool for young mothers. It provides infant behavior education, shows how mothers can be active in their child's care, enhances interactions, and help with their child's development. It has been found to reduce anxiety and health disparities also (Oswalt, McClain, & Melnyk, 2013). Primary Care Triple P is a short one-on-one parenting intervention program that consists of four sessions that involve strategies for parents of children with mild to moderate emotional or behavioral problems (Triple P, 2016). However, in one study researchers found that this program was not effective in reducing any problem behavior of children that graduated from the NICU when they were infants (Schappin, Wijnroks, Venema, Wijnberg-Williams, Veenstra, Koopman-Esseboom, et al, 2013). Shaw, et.al, (2014) were the first to examine the long-term effects of a trauma based Cognitive Behavioral Therapy (CBT) program that incorporates psychoeducation, cognitive restructuring, and exposure to trauma. The results concluded the need for this program since mothers were still exhibiting

traumatic stress symptoms at 6 month follow up. They found this program was effective in reducing traumatic symptoms of the preterm birth and NICU experience (Shaw et al., 2014).

Perspective and Reflection

The NICU

On September 13, 2015 my son was born 7 weeks and 5 days premature. Due to his prematurity his birth was somewhat unconventional when compared to a full term infant birth. Immediately following his birth he was rushed to the NICU and I was not able to see or hold him for seven long and stressful hours. I was not provided a status on him and I had no idea how he was doing. During this time for parents of full term infants, they are immediately able to hold them and initiate an infant-mother bond. I was transported to the mother and baby unit where I was not able to have my child in the same room while I could see and hear other families being able to have that special time with their newborn baby.

I was unable to go to the NICU until later on that evening. Thankfully during the days following up to birth I had received two doses of steroids prior to his birth to help with lung development, and as a result he did not require any breathing support. He was four pounds and 15 ounces, which was considered a good size for his gestational age. He was stable and the nurse that was taking care of him allowed me to have some kangaroo care time with him. Upon examining him he had an IV coming out of his left hand as well as a feeding tube and probes to monitor his heart rate, respiratory rate and oxygen rate. He seemed to be peaceful and I was very excited to finally be able to hold and touch him. When he was placed into my arms I could tell immediately he knew whom I was. He was very alert and moved in the direction of the sound of my voice. The moment was perfect, however fleeting since 20 minutes later he was taken from my arms and placed back into his incubator. Due to the inability to regulate his temperature he was required to spend some time in one. I remember feeling so guilty and empty every time I had to leave him in the NICU. I remember feeling as though his suffering was my fault since I was not able to carry him full-term even though I did everything right in regards to proper prenatal care. I kept feeling as though this was very unfair, even though the rational side of me knew that he was in the best place he could be, and that in time I would be able to take him home.

The next 22 days were spent in the NICU. To say it was traumatic would be an understatement. It was a roller-coaster ride that I will never forget. Most days you went one-step forward just to go three steps backward the next day. Nolan did not have major complications, although he had some jaundice issues and had to be placed under a phototherapy light for multiple days during his stay. During these times I was not allowed to hold him or touch him. I understood the implications surrounding the jaundice and that if untreated possible brain damage could occur. It didn't matter though, because to me I was not able to feel a bond with my child during that time, and I saw him being very uncomfortable since he had to have goggles over his eyes during that time as well. Just think how uncomfortable you would be after 24 hours straight of something over your eyes with limited relief. Some nurses would give him breaks and others wouldn't bother giving him a break. The inconsistency of care was something that I will never be able to understand. Nolan probably had up to ten different nurses during his stay. The nurses all had different ways of care and very different personalities, which did promote stress with my husband and me, since we were told different things each day. I remember feeling that I had to advocate some days for my child, and that was very stressful since you hoped that in the NICU that would not have to occur.

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Preparing for going home

I remember feeling as though the date of discharge would never come, though when it was time for him to go home I had a rush of anxiety and distress. My first thought was that I am neither equipped nor capable to care for a premature baby. He was having episodes of apnea and in order for him to be discharged he had to be sent home on an apnea monitor. This monitored his breathing and heart rate 24 hours of the day. My husband and I received a half-hour training on this machine through a representative of the company that provided the monitor and we had to show the nurses how to use the machine properly. He was prescribed a small dose of caffeine daily. We were not given any information on administering the caffeine. We were extremely intimidated, and told the NICU staff multiple times that we were not sure we are competent with the care of the monitor. Their only response was that we would be fine.

Home

Fast forward to being home for the first night. My son woke more than ten times that night. This continued on for the first six weeks. Following discharge he was put on formula due to lack of breast milk supply, and this elicited painful screams and crying most of the day due to stomach discomfort. Not once during my stay in the NICU did the staff go over techniques that I could do to help ease his discomfort or swaddling techniques to help with “back-to-sleep” since they placed him on his stomach most of his NICU stay. Thankfully, I had previous knowledge of the importance of kangaroo care, infant massage and bicycle kicks, and I would apply them frequently. After seven long weeks of discomfort, crying days and sleepless nights, on our fifth formula we were able to settle into a routine where he finally seemed to be comfortable in his home. I have a great support system with my spouse and family and my knowledge with occupational therapy were my saving graces during those first seven weeks at home. Not one staff member called to follow-up from the NICU. Not one person thought to ask me in the NICU if I was interested in any referrals or support groups that were offered for parents of premature babies. Just as the research indicates, the care and parenting is very different from a full term baby especially in the first year of life, and having adequate resources would have been most useful.

I think that mothers of premature infants are sometimes at a disadvantage when they are trying to find their niche in motherhood. The infant mother bond is very different, and can be impeded by many obstacles that begin in the NICU, and can carry on at home as well. While in the NICU sometimes parents feel that they share a parenting responsibility with the nurses since they are providing the around the clock medical care. This is both stressful and hard on parents especially, if they don't feel they are getting proper bonding time with their infant. However challenging, you continue to be there every day. You continue to do everything in your power to ensure your child is getting the best possible care they can, and you cherish the small amount of time you get to hold them every day. The more time you get with your child the stronger that bond gets and the more empowered you feel as a mother, especially when you know your child can sense you are their mother.

At home you are finally able to be the one providing the care and nurturing. This is where the doing, being and becoming really starts to happen since you are not dealing with the internal and external stressors, and obstacles that existed in the hospital. Providing care and nurturing can be intimidating since there is no manual that is sent home with you on how to care for your premature infant. However, you face similar challenges that full term parents face, and you start to feel a sense that while every child is different you feel a sense of belonging to the parenting community. The more time that you have with your infant the more you feel you are doing, being and becoming a family., However, this did not come easy, and I believe parents of premature infants could really

benefit from having services in the home that promote this notion, and help to empower parents at the same time.

Recommendations and Reality

There are some key points from the literature review to be discussed. Due to the high stress of having a very premature baby, it's suggested that the mothers should be screened for possible postnatal depression in order to implement appropriate intervention as needed (Gray et al., 2013). A postnatal screen would be a very valuable tool, and this tool could be taught and administered by multiple staff members in the NICU. There were times when I could have used someone to talk to, other than my spouse and family members, and a screen could have indicated a need to link me to a support group or the social worker. The most that the NICU staff emphasized were discharge instructions, which were general and not client specific. I do understand the importance of discharge instructions for the safety of the baby, however implementing some coping strategies or parenting techniques would have been very helpful when being at home for the first time with my premature baby. Parenting evokes stress, and teaching proper techniques to manage that stress is just as equally important as learning how to administer medications for proper care of the infant (Raines, 2013).

Many studies focused on either the mother or the mother and father as a family unit. Though one study tried to examine them separately. Gender differences should be taken into consideration since men and women use alternate methods of coping when compared to one another (Doucette & Pinelli, 2004). Men and women cope differently and this should be a consideration when performing a postnatal screen, fathers are just as important as mothers in parenting premature infants. I would suggest meeting with the parents together and separately to ensure they understand the implications that exist while caring for their premature baby at home.

A very interesting topic that surfaced during the literature review was parental perceptions having an impact on child rearing. Practitioners need to be aware that parents could restrict their child's behavior and quality of life just by their perceptions of their vulnerability (Eiser et al., 2005). While in the NICU we were told numerous times that we should not bring our child around large crowds of people especially during their first year of life. We were told that they have a higher incidence of contracting illnesses, and these illnesses can have severe and detrimental effects due to the child's prematurity. I could see some parents taking this notion to the extreme and not allowing any contact with the outside world. It's important for the parents to have a support system and to maintain balance. For this to occur, there will be times that parents need to take their child out in public. Instead practitioners could offer practical alternatives to these parents who perceive their baby as being sicker than they actually are, because this could prevent children from actively engaging in play with their peers later on when they are older.

The strain on a family can have unfavorable impacts on the family dynamics from caring for a premature child. Finances can be very strained from very expensive hospital bills. An average NICU stay is around 3,000 dollars per day, totaling to 40,000 to 80,000 if the stay is longer than four days (Managed Care, 2010). Finances are not the only strains that families face. Families reported having a moderate level of family strains, and utilizing fewer resources, and more coping strategies at 18 to 24 months post hospital discharge (Doucette & Pinelli, 2004). More importantly families that are identified as having limited access to resources should be targeted early on to enable more successful engagement in appropriate services and programs (Doucette & Pinelli, 2004). It's safe to say that the longer out from hospital discharge the fewer resources are being used even though parents are continuing to need service referrals and interventions geared towards parenting and coping with internal and external stressors.

The last key point that will be discussed is finding the right intervention for families of premature babies following their discharge from the NICU. All families regardless of demographics

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and socioeconomic status could benefit from a program that is designed to help families make the transition from the NICU to home. The Parenting Preemies Program is a creative approach to providing post NICU support and education (Willis, 2008). The purpose of Parenting Preemies is to help with the transition from the NICU to home through individualized home visits and peer support groups through team members that include a clinical social worker, occupational therapist (OT), registered dietitian, certified lactation educator, and infant massage instructor, all with training in neonatal care (2008). This program is similar to having the skilled multidisciplinary team in the NICU, except you get to do the program from the comfort of your home in the child's natural environment. The skills and confidence that parents can build through this intervention can be more valuable than anything that was provided in the NICU. It's an occupation-based intervention that is family centered approach focused on the parents and their child. Further studies should be conducted utilizing occupation-based interventions, which can ultimately help with making the transition to home from the hospital, and gives parents some help and guidance along the way.

Conclusion

Prematurity continues to be a global issue, though thanks to modern medical technology and advances, outcomes have changed and babies born at 22 and 23 weeks gestation are beating the odds and surviving. The NICU will continue to be a very traumatic experience for some if not all parents. It's important that a postnatal screen is set up to identify any distress or concerns associated with caring for a premature baby after their NICU stay. Premature babies require different and more specialized care than full term babies, who can have an altering effect on family dynamics and parenting. By providing families with appropriate and adequate resources at discharge, they can become involved in helpful interventions to ease the parenting strain that can exist with a high-risk baby. Occupation-based interventions or interventions that provide family centered care can provide the most support for families since these interventions are performed in the child's natural home environment.

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