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The Neonatal Intensive Care Unit (NICU): Self-Efficacy of Caregiving and the Lived Experience of Parents Post-NICU Discharge

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Abstract:

The purpose of this study was to identify individual (parent), environmental (NICU and home), and social factors that influence parent perceptions of self-efficacy around parent-infant co-occupations of caregiving following NICU discharge. Through a qualitative, phenomenological in-depth interview methodology, this study aimed to investigate parents' perceptions, after NICU discharge, of their lived experience with their infant within the NICU, and their resultant sense of self-efficacy in caring for their infant post NICU discharge. Seven major themes emerged from the analysis of the study data. The themes were individual: (a) balancing mixed emotions, (b) having spirituality, (c) spending time in the NICU; environmental:(d) having primary-care nursing, (e) practicing caregiving (NICU and home); and social: (f) having organizational support, and (g) having interpersonal relationships. Implications for practice include the need for elevated NICU and community practices designed to foster parental self-efficacy beliefs. Research on the instructive and supportive practices that foster parent knowledge and skill attainment, along with the development of accompanying self-efficacy is suggested.

KEYWORDS: Neonatal Intensive Care Unit, Self-Efficacy, Caregiving, Developmentally Supportive Care, Co-occupation.

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Introduction:

Parents of premature infants must develop and maintain a strong understanding of their infant's needs in order to be prepared for home caregiving.(1) At the end of what is sometimes a long stay in the NICU, parents must assume responsibility for caregiving tasks that were, up until that time, handled by NICU staff. Monitoring changes in their infant's health can sometimes override feelings of self-efficacy regarding more typical caregiving roles such as diapering, feeding, and so forth. (1,2)

The "most deeply inter-related social occupations are co-occupations," for which two or more people must be involved in the process. (3) Caregiving activities involve not only the parents' participation but also the infants and are described as co-occupations. (4) The term, co-occupation, was coined by occupational therapist and mother, Doris Pierce and is used to describe "the way in which two individuals' occupational patterns can require and be shaped by each other" (p. 3), including any task and activity that is valued within the family culture in which the parent and infant are expected to engage together. (4) The concept of co-occupation was further elaborated on by Pierce (5) by utilizing the term as part of a theoretical framework of occupations, (3) with co-occupations being the most highly interactive types of occupation.

Background:

The intense environment of the NICU can cause both psychobiological trauma to the infant, as well as emotional stress to parents. (6,7) Research has shown that, during the first years of life, parent-infant relationships may have an impact on biological growth by altering physiological or hormonal responses, eight genetic activity, (9) and neuronal networking within the brain. (10)

Additionally, separation of parent from infant in the NICU, combined with frequent occurrences of parent depression, anxiety, and stress-related incidences, affects the psychosocial development of the preterm infant. (11) An increased awareness of the escalated risk factors for parent-infant detachment, and knowledge about preventative strategies that can be initiated in the hospital are important considerations for healthcare providers in the NICU. (12) This brings importance in understanding parents' perceptions regarding their experience in the NICU, their individual feelings of caregiving self-efficacy, and ways that parents might better be supported, both while their baby is in the NICU and when home.

Purpose:

The purpose of this study was to explore parent perceptions regarding their self-

efficacy of infant caregiving post NICU discharge. Specifically gathered were, perceptions of satisfaction of NICU experience, their involvement while in the NICU, parent knowledge regarding caring for their baby both in the NICU and post-NICU, and parent perception of autonomy while parenting in the NICU. The study emerged from a noticeable lack of detail in the literature concerning what parents' experiences are once they leave the NICU, particularly regarding parent self-efficacy of infant caregiving. Such detail is needed if professionals who are involved in the care of premature infants, both within the NICU and outside the NICU, are to understand the needs that exist from a parent's perspective to support successful parent-infant dyads.

"In the high tech, biomedical and often harsh, life and death environment of the NICU, partnering with parents to facilitate parent-infant attachment is crucial."

Significance of the Study:

In the high tech, biomedical and often harsh, life and death environment of the NICU, partnering with parents to facilitate parent-infant attachment is crucial. Family-Centered Developmental Care (FCDC) provides the strong supportive foundation families in the NICU need to optimize the lifelong relationship between themselves and their babies, as well as to optimize the baby's physical, cognitive, and psychosocial development. (13,14) Embracing families as decision-making partners and collaborators in their baby's care has long been recognized as an optimal way of caring for babies in the NICU. (14) This is done through identification of individual infant/family vulnerabilities and strengths (7) and then finding ways to address these characteristics in the antepartum period, continuing through NICU admission, and on to NICU discharge and the transition home. (13)

Despite technological advances, there is the potential for psychoemotional consequences of parent-infant development while their premature baby is in the NICU. (6,7) The long-term consequences of parental stress experienced in the NICU, psychobiological trauma in the child, and decreased parent self-efficacy may influence outcomes of infants and families treated in this environment. Parent perspectives may provide useful information for professionals working in NICUs, as well as post-NICU settings (e.g., NICU follow-up clinics, pediatricians, etc.). This can hopefully lead to more sensitivity and to the development of policies and procedures in the NICU that will make it more conducive for parents to be more connected to their baby(s) and more involved in the caregiving process.

Theoretical Perspective:

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Within the framework of social cognitive theory lies the self-belief system or the perceived capability of one's personal functioning; self-efficacy; the foundation of human agency. (15) Self-efficacy beliefs regulate human functioning through cognitive, motivational, affective, and decisional processes that impact how one manages his or her own functioning and how one exercises control over events that affect his/her life. According to social cognitive theory, the environment maintains a strong influence on behavior, but also that individual cognitions are the primary factors in determining people's ability to construct their own realities and control how they respond. (15,16) Additionally, interactions among personal factors (e.g., cognition, affect), behaviors (e.g., parenting skills), and environmental influences (e.g., the NICU and home), shape human functioning. A paucity of research has included the explicit understanding of parent self-efficacy immediately post-NICU.

Parenting self-efficacy is the belief in one's ability to competently and effectively perform the cognitive, social, and motor behaviors related to being a parent. (17) For parents, self-efficacy potentially influences emotional, motivational, cognitive, and behavioral response to the caregiving role. (18) An essential component of making forward progress in the care and support of the parent/infant dyad that experiences the environment of the NICU is supporting parent perceptions of self-efficacy.

It is important to recognize that parents in similar situations (e.g., demographics and family similarities) can experience the NICU in different ways. Some parents, even within the same family unit, may rebound from the traumatic experience, and others may remain chronically debilitated, speaking to consideration of human resilience. How one responds, then, is a product not just of the event (NICU) alone, but rather an interplay between the environmental stressors and psychosocial factors. (19) As such, social cognitive theory adopts an agentic model of adaptation and change whereby individuals play a proactive role in influencing their functioning and the life circumstance they are traversing. With this in mind, pause was given to consider not just how the environment of the NICU can be changed to protect parents, but also to consider in what ways to support a parent's personal agentic perspective and enablement. Enabling a parent with personal resources to cultivate his or her competencies might very well im-

pact the shaping of the post-NICU socio-emotional resiliencies of parents.

Methods:

Design:

For this interpretive phenomenological study, informed by Heidegger's interpretive philosophy, parents of premature infants were interviewed within the first two weeks of the infants' hospital discharge from the NICU. The fundamental objective of this qualitative research was to gain insight into and understand the meaning of this particular experience (20) and the context that influences the meaning. (21)

Role of the Researcher:

The impetus for this study grew out of this researcher's past and present experience as an occupational therapist in several Level III NICUs around the country and additional NICU professional work. Sensitivities and background as a parent, an occupational therapist, faculty member, and NICU professional influenced the development of this research. A comprehensive understanding of caregiving tasks and ideas regarding levels of difficulty or challenge for parents was held. However, all interview discussions were approached seeking parent ideas of caregiving tasks so as not to limit discussions according to this researcher's perspective. Although other caregiving tasks remain to be explored, discussions will be limited only to the caregiving tasks discussed by participants. Those were sleep, bathing, feeding, diapering, and medical needs.

Participants:

Parents were the primary unit of analysis. Creswell recommended "long interviews with up to 10 people" for a phenomenological study. (22) Twelve parent participants were recruited, with a final ten participating. In total, four NICUs were utilized for participant recruitment. Two parents were referred by the neonatal therapist at NICU A. Six parents were referred by the lead neonatologist over NICU B and NICU C. Two parents were referred by a NICU nurse in NICU D. Two parents were unable to participate secondary to unexpected medical complications with their infant requiring extended and undetermined length of continued stay in the NICU (NICU C). All participants (4 male and 6 female) were selected based on the following criteria: (a) parents of premature infants, (b) infants born no less than 23 and no more than 28 weeks gestation, (c) minimum 4 week stay in the NICU, and (d) discharged from the NICU 1-2 weeks prior to interview.

In an iterative process with qualitative research, eligible participants were purposefully sampled to obtain broad representation according to demographics. The ages of parents ranged from 18 to 40 years. Ethnicities of parents included five parents who were Black/African American; 4 who were White, non-Hispanic; and one who was a non-White, Hispanic parent. Education levels of parents ranged from high school to having completed a bachelor's degree. Four parents were married, one was divorced, one was not married and was a single parent, and four were not married but were co-parenting with a partner. Six participants lived in their own home, and four lived with their own parent or another older adult parent figure.

Data Collection and Analysis:

Data were collected through semi-structured, in-depth interviews lasting between 1 and 2 hours. Interviews contained a series of questions to ask participants and were conducted in participants' homes. These questions were used to probe for further information, deeper meanings, and to use additional questions, if necessary. (20) At the beginning of each interview, parents were provided with an overview of the study, including the purpose, benefits, and potential risks (e.g., discussing emotional subjects). Informed consent and demographics forms were also reviewed and completed. Permission was received for interviews to be audiotaped and for fieldnotes to be taken. For homes where there were two participants (e.g., mother and father of infant), interviews were held one at a time and scheduled on the same day, one interview after the other, to avoid one parent informing the other about interview questions.

Analysis of the data occurred through the constant comparative method of data analysis. (23) Verbatim transcriptions were completed by this researcher, except for participant 10 who spoke only Spanish. This researcher's graduate student, who is Hispanic, transcribed that interview which was reviewed afterward. The graduate student, who was experienced in conducting qualitative interviews, participated in a pilot participant interview in order to build context to the process. In addition to initial hand coding, final coding and qualitative analysis NVivo qualitative data analysis software was used. (24)

Results:

Thematic coding analysis revealed seven overarching themes that parents identified as influencing their perceived self-efficacy of caregiving: individual: (a) balancing mixed emotions, (b) having spirituality, (c) spending time in the NICU; environmental: (d) having primary-care nursing, (e) practicing caregiving; and social: (f) having organizational support, and (g) having interpersonal relationships. Table 1 reflects themes that emerged from the data (Table).

Individual factors:

Balancing mixed emotions. All parents recalled that during the initial two weeks at home, there were fluctuating emotional states that they believed were related to having had a premature infant in the NICU. These were discussed in relation to parents' confidence and belief in their capability around caring for their baby. While each parent presented unique vulnerabilities or resiliencies, all parents expressed emotions that they believed were the aftermath of having a NICU experience. Words used to describe these shifting emotions included fear, confusion, anxiety, trauma, overwhelming, at a loss, vulnerable, sad, happy, thankful, frightened, scared, nervous, elated, emotional, hopeful, love, a failure, and powerless.

When retelling their stories about when their baby was in the NICU, the expression of fluctuating emotions was alive in their descrip-

Table 1. Overview Of Research Findings

Research	Findings

Individual factors influencing parent perceptions of self-efficacy around the co-occupation of infant caregiving?	• Balancing mixed emotions
	• Having spirituality
	• Spending time in the NICU
	  ○ For self
	  ▪ Learn roles
	  ▪ Learn routines
	  ▪ Parent peace-of-mind
	  ○ For baby's needs
	  • Baby well-being
	  • Baby knowledge of parent
	  • Nurse accountability

Environmental factors influence parent perceptions of self-efficacy around the co-occupation of infant caregiving?	• NICU
	  ○ Primary Care Nursing
	  ○ Practicing Caregiving
	• Home
	  Practicing Caregiving

Social factors influence parent perceptions of self-efficacy around the co-occupation of infant caregiving?	• Having Organizational Support
	  ○ NICU
	• Having Interpersonal Relationships
	  ○ Staff
	  ○ Support Groups/other parents
	  ○ Family/friends

Table 1: Overview of Research Findings

tions. LaTonya said she was "happy to finally have a daughter, but fearful she would not make it [survive]." Jasmine said, "I was up one minute and down the next. It was so hard to know whether to be happy or sad." "It's the craziest roller-coaster ride I have ever been on!" cried Sally when I met with her. Sally is the mother of Samuel, who was born at 26 weeks. "It felt great to have him in my arms, but I was afraid of hurting him," she continued. Similarly, her husband, Thomas, talked about his shifting emotions: "I was just emotional, and I don't get emotional usually. I was so happy to have my son, yet so worried for my wife and worried about Samuel's survival". The initial shock and experience of an early delivery and NICU experience was largely believed by parents to have contributed to their continued emotional vacillation once home.

In discussions regarding emotions, all parents reflected a common perception that their experience of having a baby in the NICU consumed them with fear and worry. Many of those emotions still continued at home. While each parent shared moments of having comfort and peace of mind in the NICU and at home, there existed a constant undercurrent of both fear and worry about their baby. Louise excitedly shared, "I simply could not wait to bring my baby home! (pause) It's a whole n'other thing when you do though (on the verge of tears). I had to do things that I hadn't even really thought of. You know, you think about your baby coming home and then reality is different."

Having spirituality. A second theme that emerged from parents was that of spirituality. Parents spoke about the individual ways they journeyed the NICU experience, often referred to by parents as "surviving" (Lawrence, Patricia, LaTonya). Charles' perspective, while intended to reflect his ideas regarding the differences between dads and moms, captured the essence of what other parents shared regarding spirituality:

As a man, we want to fix everything . . . to be the strong point in our families, and we have to put that face on, no matter how hard it is. Some days was harder than others. You know, when you see Lilly turning purple and not breathing, and you know going up and down fighting the fight that she was having, it will break any

person down. . . . I didn't really have that, uh, person or place to go to recharge, you know. My family was going through the same pain. . . . To fill me with strength, I used my spirituality more than anything else.

Spending time in the NICU. All parents emphasized the importance of being with their baby in the NICU as a means to support their confidence. Categories related to supporting themselves included learning roles and routines in the NICU and spending time in the NICU to develop peace-of-mind regarding their baby's' well-being. Categories that related to supporting their infant included the parent gaining knowledge of the baby, belief that their baby would know the parent better, and the belief that the parent being present would have an impact on the nurse's accountability to give quality care to their infant. Often, parents commented that being there for their baby brought a sense of parenting and knowledge. However, the parenting role in the NICU involved sharing responsibility with the NICU staff, and in identifying ways that set the parent apart as "the real" parent, as expressed by LaTonya.

There were unexpected parent roles that developed, such as becoming the advocate for their baby. Being able to make decisions for their baby while in the NICU brought a sense of primary parenting. In addition to the benefit of parents finding a voice as their infant's advocate, there were also factors of infant well-being that contributed to parenting confidence in caregiving. One such example was in doing Kangaroo Care. While each parent expressed different comfort levels in being in the NICU environment, they all expressed the opinion that being present with their baby while they were hospitalized helped build confidence that they would ultimately need once their baby went home.

Environmental Factors:

The primary themes that surfaced regarding factors of environment were: (a) NICU–primary care nursing and practicing caregiving, and (b) home–practicing caregiving.

Having Primary Care Nursing. While in the NICU, parents believed that their infant having a primary care nurse strongly contributed to the parents' efficacy. The idea of having primary nurses was a recurrent theme with parents, also allowing parents to feel more confident about who was taking care of their baby when they were not there. Having primary nurses allowed the parent to establish a shared understanding regarding types of information the parent needed, the timing of that information, a shared knowing of their baby, and a general level of confidence that the parent would stay informed. Sally and Thomas both mentioned that having primary nursing was key to their feeling more comfortable with Samuel as they believed the nurse knew both the parent and infant better. However, there was one point in their NICU stay where primary nursing was not offered. Sally began to cry while reflecting and said, "It's so, so hard to leave your baby with someone that you don't know how they're going to be with him [Samuel]." This was a common theme amongst parents around primary care nursing.
Practicing caregiving. Discussions regarding home caregiving were related to the amount of time they spent with their baby in the NICU and the amount of time they had practicing various caregiving activities. The more they did while in the NICU, the better they felt about being at home. Parents all described either the need to have practiced certain caregiving activities more or that having practiced activities had contributed to their confidence.

Relative to practicing caregiving, parent reflections emerged around normalcy following the NICU. Normalcy was perceived by participants in comparing themselves with how actions and activities were completed by parents who did not have infants from the NICU. Feeling like a more "typical parent" (Sally) was believed to come with the frequency with which they completed caregiving with their baby at home. However, while parents believed that increased practice would increase self-efficacy, several parents expressed that this might take extended time. Louise shared, "I can't do anything I used to do with Dillon [12-year-old son]. With Lilly, I am constantly sterilizing this and sterilizing that. It just doesn't quite feel normal yet."

A common theme was reported around sleep. All 10 parents reported fears related to allowing themselves to sleep when their baby was asleep at night. The primary fear was that the baby might stop breathing. The second most predominant concern was regarding feeding. Eight of the 10 parents expressed concern that they were not feeding their infant in the correct manner, or that they were not meeting a feeding schedule such as that experienced in the NICU.

Although finding normalcy was expressed through emotions of sadness and wanting, there were also joyous emotions regarding being home and doing some "normal parent thing" (Thomas). Charles captured this best when he suddenly asked, "Have you seen Lilly's room? I had so much fun putting her room together! For the longest time, I didn't do anything in there [her room]. We didn't know from one minute to the next sometimes if she would be coming home, but when we got word that she was close to discharge, I went to town on that room. It made me feel so good to see it done (pause). It still does."

Social Factors:

Social factor themes emerged around having organizational support and having interpersonal relationships.

Having organizational support. Relative to social support, parents frequently talked about the manner in which the NICU was organized. Parents spoke primarily regarding space needs, as well as policies regarding visitation. Most supportive were those NICU's who allowed parents to come and go at any time. Six of the parents expressed sadness with being "kicked out of the NICU" (Jasmine) and desired to know what was going on during those times. Parents also spoke about the discharge process in terms of so-

cial support. Most parents believed that educational material they received was "enough". However, parents were not prepared for what they encountered when getting home. Charles shared, "All I wanted to do was bring Lilly home! They kept making us stay day after day to room in. By that point in our stay, we knew what to do, so I didn't understand why we couldn't be discharged." He continued, "But there's something missing or something wrong. When we got home, it's like we hit a brick wall. I know we got good information and educational stuff at discharge, but why was it that we were so anxious when we got home? . . . It's like we never heard anything!"

Having interpersonal relationships. Four sources of interpersonal relationships were identified as themes; (a) relationships with staff, (b) support groups/other parents, (c) spouse/partner, and (d) family/friends.

Relationship with staff. All parents explicitly listed communication as a source of both increased and decreased confidence. Parents strongly held that their baby's health and well-being depended on relationships with NICU staff. Some parents felt strong enough to have tough conversations with staff, like Charles and Louise. Other parents were explicit about not wanting to upset anyone, and so they chose to stay silent.

Charles' example reflects collective parent perceptions regarding their communication relationships with/about staff:

You know, we were very fortunate with Dr. Tom. He would pull a chair in with us, and we could talk about anything and everything. And that level of communication just gave such a level of comfort to my wife and me that we were okay during the day [when we were not there]. You know, I was okay going to work knowing what the plan was. The last thing you want is to leave at one point and she's [baby] on CPAP, and come back and she's on a ventilator and you never even got a phone call or never nothing. You're like, what just happened here, you know? But I'll be honest, a lot of that is changed by the nurses that we have for good and bad. If we had a good nurse and somebody that would take their time and you knew we'd get her [baby] situated just right, everything was fine. But then there's also this time when we had a nurse that was like, "Okay, we're going to kangaroo," slap her on you, and didn't really have a concern for where the tubes were. Were they pulling on her? Were they pulling on her nose where she had the CPAP, …those type of things.. (Charles)

Support groups/other parents. All parents recommended support groups or opportunities for parents to meet other parents, however, only one NICU offered such. When asked what they would share with new parents to the NICU, Louise shared, "Know that it's going to be where you will have good days and bad days. And the bad days, are always, always, bad. I know the bad days for me were terrible. It's going to be great, great, and then it plummets."

Spouse/partner. In the study, there were two married couples, one couple who lived separately with their respective parents, one couple who lived together occasionally but were mostly residing with their parents, one mother who was divorced, and one mother whose baby's father was not involved. All but Patricia and LaTonya, the single mothers, spoke of their own efficacy as an extension of their confidence in their mate.

Family/friends. Parents' ideas of support from family and friends were related to both the NICU environment and the home environment. Parents generally felt that support came more into play when the baby was at home. Family and friends could often not understand or appreciate the emotions that parents were going through while their baby was in the hospital.

Conclusion:

Trauma-informed care recognizes that all NICU families are traumatized by the birth of a baby who requires admission to a NICU, and often by the NICU experience itself. (7) A substantial body of research verifies that perceived self-efficacy is a common mechanism through which mastery experiences, vicarious experiences, and social resources improve psychosocial functioning. (15)
In consideration for literature that reflects how early experiences impact future relationships, (25,26,27) information related to how parents experienced the environment of the NICU in relation to having their baby home from the hospital was deemed important. As an occupational therapist and neonatal therapist, particular attention was given to discovering individual, environmental, and social factors that served as facilitators or barriers to self-efficacy in the co-occupation of caregiving between parent and infant. Throughout the interviews, parents revealed much about these factors that were particular to their situations and in relation to caregiving tasks important to them. Of the 10 parents interviewed, all spoke of the fear they felt when bringing their infant home. While they believed that they had been educated regarding caregiving, they described the difficulty in caring for their baby immediately post-NICU discharge.

Bandura's summary regarding the importance of self-efficacy brings relevance to understanding the needs of NICU parents, particularly when they are home from the NICU and caring for their infants on their own:

People make causal contributions to their own psychosocial functioning through mechanisms of personal agency. Among the mechanisms of agency, none is more central or pervasive than beliefs of personal efficacy. Unless people believe they can produce desired effects by their actions, they have little incentive to act. Efficacy belief, therefore, is a major basis of action. People guide their lives by their beliefs of personal efficacy. (15)

Consistent with literature in the area of self-efficacy, (28) no clear formula emerged from this study that explicates how individual, environmental, and social factors combine to influence a parents' increased self-efficacy. It is clear, however, that factors from all three have bearing on the parent's perceptions in differing ways.

For example, while one parent expressed appreciation for the education he or she received from staff in the NICU, another parent described the education as less informative and how his or her own personality and other social factors came into play in his or her confidence levels. Results from this study inform professionals both within the NICU and in the community about possible ways that individual, environmental, and social factors might influence parents' perceptions of self-efficacy.

The importance of continuity of care for the neonatal intensive care unit (NICU) baby after discharge has long been recognized by hospitals and community health care providers. Although survival of premature infants in the NICU has strongly been the focus of NICU personnel, there is growing emphasis in understanding outcomes to both infants and parents post NICU discharge. (29) NICU parents are at higher risk for postpartum depression (PPD) and posttraumatic stress disorder (PTSD) during the NICU stay and afterwards, even if their baby was in the NICU only briefly. (30) Psychological distress in NICU parents is associated with a deteriorating cycle of disruptions in the parent-infant relationship, subsequent impairments in child development (cognitive, emotional, physical, and behavioral), and reciprocal negative effects on parental emotional and physical health. (31) A proactive approach to interrupting that cycle must be taken by supporting parents in the NICU and in the home environment afterward. A concerted effort in understanding the continuum of parent-infant needs, both within the NICU and post-discharge, is needed in effort to support healthy parent-infant relationships. An important predictor of how the infant grows and develops after being in the NICU is the quality of the infant's psychosocial environment, and in particular, the context of the parent-infant relationship.

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