2021

What Is the Lived Experience of Mothers of Premature Infants in a Level-IV Neonatal Intensive Care Unit

Jennifer Lorraine Nelson
Nova Southeastern University

What Is the Lived Experience of Mothers of Premature Infants in a Level-IV Neonatal Intensive Care Unit?

by

Jennifer L Nelson, MOT, OTR/L, BCP, CNT

Submitted in partial fulfillment requirements for the degree of
Doctor of Philosophy in the
Department of Occupational Therapy
Dr. Pallavi Patel College of Health Care Sciences
Nova Southeastern University

March 2021

NOVA SOUTHEASTERN UNIVERSITY
HEALTH PROFESSIONS DIVISION
DR. PALLAVI PATEL COLLEGE OF HEALTH CARE SCIENCES
DEPARTMENT OF OCCUPATIONAL THERAPY
FORT LAUDERDALE, FL 33328

This dissertation, written by Jennifer L Nelson under direction of her Dissertation Committee, and approved by all of its members, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF PHILOSOPHY

DISSERTATION COMMITTEE

_____ _____
Kristin Winston, Ph.D., OTR/L, FAOTA Date
Chairperson of Dissertation Committee

_____ _____
Elise Bloch, Ed.D., OT/L Date
Dissertation Committee Member

_____ _____
Jenene Woods Craig, Ph.D., MBA, OTR/L, CNT Date
Dissertation Committee Member

NOVA SOUTHEASTERN UNIVERSITY
HEALTH PROFESSIONS DIVISION
DR. PALLAVI PATEL COLLEGE OF HEALTH CARE SCIENCES
FORT LAUDERDALE, FL 33328

Certification

We hereby certify that this dissertation, submitted by Jennifer L Nelson, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the dissertation requirement for the Doctor of Philosophy degree.

Approved:

_____ _____
Rick Davenport, Ph.D., OTR/L Date
Ph.D. in Occupational Therapy Program Director

_____ _____
Rebecca Estes, Ph.D., OTR/L, CAPS Date
Chair of Department of Occupational Therapy

_____ _____
Peter Taylor, Ph.D. Date
Executive Associate Dean for Academic & External Affairs

_____ _____
Guy M. Nehrenz, Sr., EdD, MA, RRT Date
Interim Dean, Dr. Pallavi Patel College of Health Care Sciences

Abstract

The purpose of this qualitative study was to gain knowledge of the lived experience of mothers of premature infants in a Level-IV neonatal intensive care unit (NICU). Additionally, the purpose of the dissertation study was to have a more in-depth understanding of mothers' experience of mothering in a Level-IV NICU. The eight participants were mothers of premature infants in a Level-IV NICU who had been admitted for a least one month. Data sources for the dissertation study were a demographic form, the primary investigator's journal, two individual semi-structured interviews, and fieldnotes. The person-environment-occupation model and an occupational theory of human nature were used to frame the research design. The investigator found five themes and two subthemes, which were *unanticipated journey to becoming a mother, emotional rollercoaster, mother's lost voice, cultural influences, roadblocks to mothering, unexpected layer to mothering occupations,* and *support from mothering occupations*. Each theme used had a description of a mother's experience with mothering occupations and co-occupations in a Level-IV NICU. Occupational therapists can improve occupation-based practice in the NICU by incorporating mothering occupations and co-occupations between mothers and their premature infants.

Keywords: phenomenological, mothering, mothering occupations, co-occupations, premature infants, NICU, person-environment-occupation model, an occupational theory of human need, occupational therapy, occupation-based practice

Acknowledgements

This journey would not have been successful without the support from many special people in my life. I would like to mention my late grandmother, Billie Nelson, who gifted me the love of reading and learning as soon as I was old enough to accompany her to the library. She educated me on the importance of obtaining knowledge and expanding my mind to achieve any goal one sets forth to achieve. My parents, Louise and Don Nelson, have stood by my side through all of my endeavors even if they seemed farfetched. They are my biggest supporters, and I would not be who I am today without their love and encouragement. My brother, Andy, who has been nothing but proud of my accomplishments. I would like to thank Charles, my fiancé, for listening to me ramble on for hours about data, writing, and editing. You have been my rock through the most stressful parts of this journey, and for that and many other reasons, I love you very much. I would like to thank my friends, whom many of their names are used as pseudonyms in this paper, for understanding my absence from many social gatherings. I was there in spirit!

To the mothers who graciously shared their stories with me, I will be forever grateful. I would like to thank them from the bottom of my heart for being willing to share the most intimate details of their lives with me. They told their stories with such raw emotion and grace. I would like to honor the babies who lost their lives during and following the completion of this paper. I am honored to have known you and your family. I am a better neonatal therapist because of this entire experience.

I would like to thank my committee members for all of their hard work and dedication to seeing me through this journey. Dr. Kristin Winston, Chair, who supported my deadlines and held me accountable to meeting my goals. Thank you for pushing me and keeping me on track. You are a brilliant OT and I could not have asked for a better mentor! Dr. Elise Bloch, 2nd Chair,

who gave the most incredible insight on family-centered care. Thank you for allowing me to pick your brain and giving the best feedback from your wealth of knowledge. Dr. Jenene Woods Craig, 3rd Chair and NICU expert, who opened my eyes to view neonatal care in a new light. Thank you for pushing me to think more broadly and how to apply my newfound vision to improve NICU care. I could not have achieved my goals without you three! I look forward to our continued work together.

Thank you to all of the faculty at Nova Southeastern University for your support and guidance during this program. I have thoroughly learned so much from each one of you. Thank you, Dr. Davenport, for keeping me organized since Day 1. Thank you to my hospital, neonatal therapy team, and occupational therapy team for allowing me to wear many hats during the past few years. I am very thankful for being a part of such an incredible neonatal team and occupational therapy team!

Table of Contents

List of Tables

List of Figure

Chapter 1: Problem and Domain of Inquiry

Problem and Domain of Inquiry

Having a premature infant admitted to a Level IV neonatal intensive care unit (NICU) is a stressful and unanticipated event for mothers (Harris et al., 2018). As a woman visualizes becoming a mother, rarely to do they envision navigating a medically driven environment (Holditch-Davis et al., 2011). The NICU environment is designed to provide life-saving interventions that result in mothers feeling as though their role is lost to medical staff (Miles et al., 2011). Prolonged hospitalizations are a direct result of premature infants being resuscitated at earlier gestational ages (Pineda et al., 2018). These lengthy hospitalizations may result in an undue hardship on mothers when obligations outside of the hospital prevent bedside presence and participation (Harris et al., 2018).

Lengthy hospitalizations may cause an unwarranted burden that have a significant role in a mother's ability to be present at the bedside (Reynolds et al., 2013). While family-centered care has become the gold standard in the NICU, encouraging a mother to constantly be at the bedside can sometimes be overwhelming (Heinemann et al., 2013). Therefore, the NICU may be perceived as a tremendous hurdle by women in learning how to become mothers to their premature infants (Gibbs et al., 2016). With this qualitative study, the investigator sought to understand the lived experience of mothers of premature infants in a Level IV NICU. The background of prematurity and mothering, rationale for the dissertation study, and the research questions are reviewed in this chapter.

Problem Statement

The United States (US) is experiencing an increase in preterm births from 9.6% in 2015 to 9.9% in 2017 with more than 380,000 premature infants being born each year (March of

Dimes, 2018). With the advancement of medical interventions, premature infants are being resuscitated at earlier gestational ages, which correlates with longer hospitalizations in the NICU (Altimier & Phillips, 2013). Prolonged hospitalization of premature infants may result in a burden on mothers who have a plethora of obligations at home (Reynolds et al., 2013). Limited time at the bedside may leave the mother feeling less competent in performing mothering occupations for her premature infant (Gibbs et al., 2015). Fathers of premature infants or significant others also play an important role in long-term developmental outcomes as well as support for the mother (Sisson et al., 2015). However, for this dissertation study, the experience of the mothers of premature infants who identify as the primary caregiver in a Level IV NICU was the focus.

As mothers prepare for motherhood and visualize bonding experiences with their infants, rarely are the masses of medical professionals, distressing medical procedures, and tense environment of the NICU taken into consideration (Pineda et al., 2018). Premature infants are typically removed immediately from their mothers directly following birth due to medical complications and the need for medical interventions (Heinemann et al., 2013). Mothers are often leaving the hospital without their premature infants due to the ongoing medical care the infants require for survival (Holditch-Davis et al., 2011; Miles et al., 2011; Spinelli et al., 2016). Relying on medical staff to care for the premature infant may lead to perceptions by mothers around their inability to fulfill her maternal role (Gibbs et al., 2016). A mother's role of being a caregiver is often affected by the fragility of the premature infant who requires medical care for survival (Spinelli et al., 2016).

Having an infant in the NICU has a profound effect on a mother's confidence in becoming the primary caretaker for her infant in the NICU (Ward, 2001). The medically driven

NICU has left mothers feeling their role in their infant's care was undefined, and they had little place for mothering in this environment (Gibbs et al., 2010). Many authors have stated that maternal presence involves being present at the bedside of the infant (Reynolds et al., 2013) as well as participating in the care for the infant (Pineda et al., 2018). Therefore, it can be suggested that being present and participating in care may have long-term implications for not only the mother but also the premature infant (Wigert et al., 2010). In a descriptive study, 67 parents of 42 infants in the NICU were studied to evaluate parental presence and where the parents stayed during the hospitalization, such as home, the birthing hospital, the parent room on the unit, or a hotel (Wigert et al., 2010). The authors found that parents who were able to stay in the parent room in the NICU were present the most out of the participants (Wigert et al., 2010). The authors also interviewed the parents to explore reasons for presence, the facilitation of presence, and the obstruction of presence (Wigert et al., 2010). The authors found that there were many barriers to presence, such as care for other children at home, poor treatment by medical staff, a non-family-friendly environment, and distance from the hospital (Wigert et al., 2010).

These findings are also echoed in other articles. Barriers to bedside presence and participation have been stated in the literature to include feelings of being overwhelmed by stress, guilt, child care limitations, financial strain, employment obligations, and multiple responsibilities (Pineda et al., 2018). Barriers to parent bedside presence prevents physical closeness between the mother and her premature infant (Feeley et al., 2016; Reynolds et al., 2013). Physical closeness between the mother and her premature infant is used to support the mother-infant relationship, maternal confidence, and the maternal role (Spinelli et al., 2016). Therefore, exploring the mother's experience of having a premature infant in a Level IV NICU may lead to a better understanding of supports and barriers to parent bedside presence and

participation, which can facilitate mothering occupations and improve long-term developmental outcomes of the premature infant.

Purpose of the Study

The purpose of this dissertation study was to gain knowledge of the lived experience of mothers of premature infants in a Level IV NICU. Additionally, the purpose of the dissertation study was to have a more in-depth understanding of mothers' experience of mothering in a Level IV NICU. The context for this dissertation study was a Level IV NICU in an urban setting, which is underrepresented in the literature to date. It is imperative that occupational therapists support and facilitate mothering occupations, which enhance a mother's capabilities to care for her premature infant. The findings of this dissertation study will assist the occupational therapist in formulating a more holistic approach to practice in the NICU to include mothering occupations, co-occupations, mothering identity, and the maternal role for the care of the premature infant.

Research Questions

There is an academic gap in the literature in understanding the lived experience of mothers of premature infants in a Level IV NICU, which lends to the following research questions:

1. What is the lived experience of mothers of premature infants in a Level IV NICU?
2. What is the mothers' experience of performing mothering occupations in the Level IV NICU?

Significance of the Study

Education

The findings from this dissertation study were used to highlight the experience of mothers of premature infants in a Level IV NICU. Many authors have indicated that mothers of

premature infants in a Level IV NICU often have significant barriers to bedside presence due to the prolonged hospitalization of their infant (Pineda et al., 2018; Reynolds et al., 2013; Spinelli et al., 2016). With the findings of this dissertation study, the investigator may identify potential barriers and supports to bedside presence, which will be important information for NICUs when educating all neonatal medical staff in caring for premature infants and their mothers. The findings may also be useful to support the development of educational programs to facilitate mothering occupations, co-occupations, and the maternal role of premature infants in a Level IV NICU. Furthermore, the findings of this dissertation study may also be useful to support the development of an educational and training program for mothers to learn how to care for their premature infants in a Level IV NICU.

Practice

The investigator sought to understand mother's experiences with becoming a mother while parenting in a Level IV NICU. Understanding how to support mothering at the bedside of the premature infant may improve an occupational therapist's practice in neonatal therapy. Occupational therapists can foster the maternal role in the Level IV NICU environment, which may be supported by the findings of this dissertation study. Additionally, strengthening family-centered and developmental care in the Level IV NICU may also be affected by the findings of this dissertation study.

Research

The findings from this dissertation study may support future research to gain specific knowledge into mothering occupations of premature infants. Future research may also include how mothers of premature infants in a Level IV NICU perceive family-centered care, developmental care practices, and support from medical staff. The findings may also identify

other areas for future research, such as the Level IV NICU resources, environmental barriers and supports, and hospital policies.

Public Policy

A Level IV NICU in an urban setting consists of a population of mothers and their premature infants from variety of cultural backgrounds, different socioeconomic statuses, and varied educational backgrounds. The findings of this dissertation study may show the importance of how and why occupational therapists should recognize the barriers from the social, economic, and political barriers that affect the lives of mothers of premature infants in a Level IV NICU. Occupational therapists may use the findings from this dissertation study to apply for grants for educational programs that are aimed at improving health literacy for underserved communities and populations. Occupational therapists may use the findings from this dissertation study to lobby for federal and state level policies, focusing on support for mothers of premature infants and maternal mental health. Federal and state level policies may also focus on addressing infant mental health to include additional support for the long-term developmental needs of premature infants. The findings from this dissertation study may highlight the importance of changing hospital policies to support mothers of premature infants.

Philosophical Underpinnings

The qualitative paradigm has an assumption that there are multiple realities that are experienced by individuals (Richards & Morse, 2013). The ontology of qualitative research is centered on interpretivism (Luborsky & Lysack, 2017). Interpretivism is explained as there is no single reality, and each person experiences life differently (Cohen et al., 2000). The epistemology of qualitative research is based on obtaining knowledge from an inductive process (Teddlie & Tashakkori, 2009). Inductive logic is a bottom-up approach of obtaining knowledge

from observations within the world (Creswell, 2013). The bottom-up approach is used when analyzing observations in order to explain a phenomenon (Creswell, 2013). The observations become a method for formulating new concepts, ideas, or theories (Luborsky & Lysack, 2017). The method of qualitative research is the way in which the inquirer obtains knowledge of the world (Luborsky & Lysack, 2017). A phenomenology philosophy method of inquiry involves seeking to understand the lived experiences of individuals in their world; therefore, this investigator sought to understand the lived experience of mothers of premature infants in a Level IV NICU.

Research Tradition

For the research design, a qualitative, hermeneutic phenomenological approach was used to interview mothers of premature infants in a Level IV NICU. Hermeneutic phenomenology explained by van Manen in 1990 is a method based on the ability to understand the lived experience of individuals in their everyday lives (Richards & Morse, 2013). Moreover, hermeneutic phenomenology is grounded on the ability to understand the world as it is presented to us (Cohen et al., 2000). Hermeneutic phenomenology was deemed most suitable to explore the lived experience of mothers of premature infants in a Level IV NICU.

Definitions of Terms

Level IV NICU

A Level IV NICU consists of personnel and equipment that presents continuous life support, comprehensive care for extremely high-risk newborn infants, infants born weighing less than 1500 g or born less than 32 weeks' gestation, and presented specialized surgical interventions (American Academy of Pediatrics, 2012).

Premature Infant

A premature infant is a neonate born alive less than 37 weeks' gestation (World Health Organization [WHO], 2018). Premature infants are considered moderate to late preterm when born between 32- and 37-weeks' gestation. Premature infants born between 28- and 32-weeks' gestation are considered very preterm. Premature infants are defined as extremely preterm when born less than 28 weeks' gestation (WHO, 2018).

Developmental Care

Developmental care is defined as an integrative approach to providing care for premature infants in the NICU that incorporates positioning, sleep, feeding, decreased pain and stress, attention to skin, and collaborating with families (Coughlin et. al., 2009).

Family-Centered Care

Family-centered care is described as a model of care in which the family unit is central in formulating a caregiving plan for the infant as well as the bonding process between the mother and her premature infant (Coughlin et al., 2009).

Mothering

Mothering is defined in the literature as a socially constructed term in which one assumes the responsibility of caring for, nurturing, and protecting children (Dunbar & Roberts, 2006; Francis-Connolly, 2009; Ruddick, 1995; Winston et al., 2010).

Occupation

Occupation is the goal-directed, self-motivating, functional activity an individual engages in everyday and in their families and communities to provide meaning, occupy time, and bring purpose to life (American Occupational Therapy Association [AOTA], 2020).

Co-Occupation

Co-occupation is defined as an occupation that is completed between two individuals (Pierce, 2009). Co-occupations between mother and infant have been described as interdependent activities that nurture, such as feeding and eating, comforting to sleep (Olson, 2004), snuggling, soothing, (Francis-Connolly, 2000), and any other synchronic activity that facilitates an infant's occupational development (Price & Stephenson, 2009). Co-occupations have been further described as caring activities that focus on the mother-infant interaction, which has feelings of satisfaction and competence (Fraga et al., 2019) as well as mother-infant activities that focus on a mutual physical, emotional, and intentional interaction (Price & Miner, 2009).

Summary

Admission to a Level IV NICU due to prematurity may cause stress on mothers, which can alter typical mothering occupations and caregiving tasks, which is especially relevant when mothers experience multiple barriers from being able to be present at the bedside consistently to care for their premature infant. Identification of supports and barriers may lead to decreased maternal stress and improve empowerment of maternal control, which in turn may influence the overall satisfaction during a NICU stay. Therefore, understanding the lived experience of mothers of premature infants in a Level IV NICU becomes vital to not only occupational therapists but also to the medical staff in this technological environment.

Disclaimer

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), also known as COVID-19, is a novel respiratory infection, which often leads to pneumonia, fever, cough, and hospitalization (Hoang et al., 2020). The World Health Organization has identified COVID-19 as a worldwide pandemic and a global health crisis (Hoang et al., 2020). The occurrence of

COVID-19, which emerged in December 2019 in China, eventually infiltrated the US in early 2020. Transmission of COVID-19 occurs through inhalation of infected droplet and direct contact with infected surfaces (Sankar et al., 2020). Infection control measures and the use of personal protective equipment (PPE) have been suggested as a first line of defense in the prevention of spreading COVID-19, which includes maintaining social distance, wearing face coverings, washing one's hands, avoiding touching the face, and frequent cleaning of surfaces (Sankar et al., 2020). Thus far, children have been thought to have a low incidence of infection; however, asymptomatic children may still transmit COVID-19 to others (Nakra et al., 2020). Due to the novel COVID-19, medical facilities have deployed new policies around visitation and infection control measures. These new policies have directly influenced this qualitative study.

Chapter 2: Review of the Literature

Introduction to the Chapter

The purpose of this dissertation study was to explore the lived experience of mothers of premature infants in a Level IV NICU. This chapter reviews relevant literature from the fields of occupational science, occupational therapy, nursing, psychology, neonatology, social work, and public health. The electronic databases accessed for the search of the literature were CINHAL, PubMed, EBSCO, Google Scholar, and ERIC. Keywords that were used in the search included "mothering," "NICU," "prematurity," "parental presence," "bonding," "maternal role," "maternal identity," "co-occupation," "family-centered care," "developmental care," and combinations of them all. The chapter is divided into three sections. The first section has a focus on the review of the literature on mothering and mothering occupations. The second section includes the review of the literature on premature infants and the NICU. The third section includes the review of the literature on the person-environment-occupation (PEO) model of care and the occupational science theoretical perspective of an occupational theory of human nature.

Mothering

Mothering has been defined in the literature as a socially constructed term (Chodorow, 1978) where one assumes the responsibility of raising and safeguarding children (Ruddick, 1995). Mothering is further detailed in the literature as being expressed by society's expectations (Chodorow, 1978), cultural norms (Collins, 1994), and gender expectations (Ruddick, 1995). Mothering has also been described in the literature as being viewed as mother's work (Ruddick, 1995), which involves caring for children, fostering their growth and development, and providing them a socially acceptable upbringing (Francis-Connolly, 2004). Often, mothering is viewed as a paramount event that is evident throughout a woman's life (Horne et al., 2005), and

has a central role in a woman's life (Avrech Bar et al., 2016). Additionally, mothering can be viewed through the sociocultural lens as mother's work that is influenced by a plethora of factors, which include culture, community, and socioeconomic status (Esdaile et al., 2004).

Mothering occurs within all cultures. Culture has a vital role in shaping the view of mothering (Price & Stephenson, 2009). Cultural beliefs and habits form the idea of that which is considered typical mothering occupations and that which is accepted as normal (Price & Stephenson, 2009). Furthermore, culture has shaped how mothers and their families interact within their communities (Price & Stephenson, 2009). In an expert opinion paper, the authors stated most mothers learn how to become mothers from their own experience of growing up within their family context (Barrett & Fleming, 2011). Hence, mothering may be considered a learned occupation within an individual's cultural context (Francis-Connolly, 2009). Collins (1994) discussed the influence of racial ethnic communities on mothering and how a woman may experience mothering through the lens of her ethnic backgrounds. Moreover, Collins (1994) discussed how mothering was influenced by one's socioeconomic status when navigating the upbringing of children. Arendell (2000) stated that social class affects the mothers' resources available to them for caring for their children. Although familial, social, and cultural contexts influence mothering, the process of entering motherhood is similar regardless of contextual factors (Esdaile et al., 2004).

A woman begins the path to motherhood prior to the arrival of the infant by engaging in anticipatory occupations, such as preparing to become pregnant, restructuring the lifestyle while pregnant, and preparing the household for the arrival of the infant (Esdaile et al., 2004). In a mixed methods study with six first-time mothers, the authors explored occupational changes for mothers as they entered motherhood (Horne et al., 2005). The authors found that first-time

mothers experienced significant occupational role changes as they adapted to becoming a mother. Motherhood has been stated in the literature as a significant life role that evolves and changes over the lifespan (Francis-Connolly, 2004). Mothering and the meaning one places on mothering is unique and largely depends on life situations (Avrech Bar et al., 2016). A life situation that will have a direct impact on mothering and entering motherhood is the birth of a premature infant (Avrech Bar et al., 2016). Premature birth disrupts the natural progression to motherhood as it terminates pregnancy early and often leaves a woman feeling ill-prepared to take on motherhood (Miles et al., 2011). Separation of the premature infant and the mother is often immediate and for a prolonged period of time, days to months, depending on the medical complexity of the premature infant (Craig et al., 2015). Medical complexity of the premature infant and the medical status of the mother following birth of the premature infant often becomes a barrier to participation in mothering occupations (Spinelli et al., 2016).

In the occupational science and occupational therapy literature, mothering has been identified as an occupation (Dunbar & Roberts, 2006), which can be described further under the category of instrumental activities of daily living (IADLs) as *child rearing* (AOTA, 2020). Using grounded theory methodology, 17 women were either interviewed or participated in focus groups to explore mothering experiences (Francis-Connolly, 2009). The results indicated that mothering is an occupation that never ends even as the mother grows old and the demands of caregiving changes (Francis-Connolly, 2009). Mothering occupations are described in the literature as tasks and activities, such as cooking, cleaning, keeping the child safe, providing clothes, managing the household, and showing affection to name a few (Horne et al., 2005; Sethi, 2019). Additionally, mothering occupations are often viewed as unpaid work that ensures nourishment, growth, development of children, and the unpaid work that maintains the household (Primeau, 2004).

Engagement in mothering occupations is often restricted when the premature infant is admitted to the NICU (Gibbs et al., 2010) and the medical status of the mother following the delivery of the premature infant, which often results in prolonged separation of the mother and her infant (Spinelli et al., 2016). Furthermore, co-occupations, such as diaper changes, feeding, and bathing, are often prohibited by medical staff in the NICU due to the fragility of the premature infant (Gibbs et al., 2010). Therefore, limited engagement in co-occupations often results in the mother feeling as though her role is lost to medical professionals (Spinelli et al., 2016; Wigert et al., 2010). Moreover, performing mothering occupations is enhancing a woman's role of being a mother (Horne et al., 2005). Dunbar and Roberts (2006) interviewed seven women about their perceptions of mothering and the significance of the role of being a mother. In their qualitative study, maternal role management was identified as a theme that highlights the importance roles have in mothering (Dunbar & Roberts, 2006).

Participation in occupations has been stated as a means to enhancing *roles* AOTA, 2020). Roles have been described as a set of behaviors that are defined by individuals as a result of their culture and context (AOTA, 2020). Horne et al. (2005) stated that becoming a mother results in a sudden change in roles, which can be unfamiliar to the new mother. New mothers and mothers of premature infants experience similar changes in their roles. Horne et al. (2005) studied six mothers in a mixed methods study to explore occupational changes for first-time motherhood. The authors found that adjusting to motherhood is difficult, and significant changes in roles occur after the birth to the infant (Horne et al., 2005). These findings are similar to a qualitative study interviewing mothers of premature infants (Heydarpour et al., 2017). The authors found through interviewing 17 mothers of preterm infants, becoming a mother to a premature infant has a requirement for significant adaptation to the maternal role (Heydarpour et al., 2017). Both

authors suggest supporting the transition to motherhood and the maternal role should be considered in future research (Horne et al., 2005) and occupational therapy practice (Avrech Bar et al., 2016).

One way to overcome unfamiliar feelings while adjusting to motherhood and assuming the maternal role is for the mother to engage in caregiving occupations (Horne et al., 2005) and co-occupations with her infant (Price & Miner, 2009). *Co-occupations* have been defined as occupations that are completed between two individuals (Pierce, 2009, p. 204). The engagement of co-occupations between the mother and the infant is a bi-directional relationship that serves as a transactional experience (Price & Miner, 2009; Price & Stephenson, 2009) for improved long-term developmental outcomes and improved infant mental health. In a multiple case study report, six mothers participated in semi-structured interviews to explore mothering co-occupations, which resulted in the importance co-occupations have on oneself in identifying as a mother (Fraga et al., 2019). The co-occupations between mother and infant were described by the authors as being mutually interconnected by physicality, emotionality, and shared intentionality between the two (Fraga et al., 2019). The authors discussed that mothers often feel frustrated by the restrictions the medical staff place on participation of co-occupations in the NICU (Fraga et al., 2019). These findings highlight the need for facilitation of mothering occupations and co-occupations in the NICU to enhance mothering opportunities. Co-occupations between the mother and her infant are also shaped by the mother's family unit, the community to which the mother belongs, and the mother's culture (Price & Stephenson, 2009). Culture has a significant role in the mother's view of mothering and how she engages in co-occupations with her infant (Price & Stephenson, 2009). Engagement in co-occupations between the mother and her infant is used to assist the mother becoming in tune with her infant and identifying herself as the mother

(Mercer, 2004). Furthermore, the relationship between occupation and self-identity has been explained in the literature as being significant (Christiansen, 1999) and can be applied to mothering and the development of mothering identity (Horne et al., 2005).

Occupation and Identity

Occupation as Identity

Christiansen (1999) discussed occupation as identity by emphasizing the connection between engagement in occupation and one's personal and social identity. Participation in occupation has supported the development of identity, which in turn gives meaning to one's life and wellbeing (Christiansen, 1999). Additionally, Christiansen (1999) postulated four important factors for occupation as identity: (a) identity is shaped by interpersonal relationships with others, (b) identity is closely related to activities we do, (c) identity gives meaning to individual life stories and meaning to everyday life, and (d) identity serves a direct purpose for the promotion of well-being and satisfaction (pp. 548-550). Phelan and Kinsella (2009) explored occupational identity from an occupational science and socio-cultural perspective in which they determined that identity is often shaped through occupation. The authors further discussed occupation as identity as a way to envision an individual's future self and possible life stories (Phelan & Kinsella, 2009). The concept of occupation as identity as stated by Christiansen (1999) and further explored by Phelan and Kinsella (2009) is used to support the development of mothering identity.

Mothering Identity

Mothering identity is defined in the literature as the mother's beliefs and feelings of herself as a mother to her infant (Mercer, 2004). Identifying oneself as a mother results in emphasis on the ability to care (Chodorow, 1978), nurture (Glenn, 1994), and protect children

(Ruddick, 1995). Mothering identity can be described as assuming the nurturing and maternal work for the care of children (Ruddick, 1995), which has a sense of self (Collins, 1994). Mothering identity often begins prenatally and continues through the first year following the birth of the infant (Cabrera, 2018). Mothering identity is strengthened by her ability to care and nurture children (Arendell, 2000). Consequently, mothering identity forms early and establishes how a mother responds, interacts, and predicts the needs of her infant (Mercer, 2004). Through engagement in mothering occupations, mothering identity forms, evolves, and strengthens over time (Avrech Bar et al., 2016). The establishment of mothering identity is used to assist in the formation of the mother-infant relationship (Chodorow, 1978). The mother-infant relationship is instinctually interdependent in which gratification is mutual between the mother and her infant (Chodorow, 1978). Therefore, through the ability to care for her children, a mothering identity develops and feelings of attachment forms.

Feelings of attachment to the infant strengthens mothering identity (Miles et al., 2011). In the mixed methods study, Miles et al. (2011) studied 81 mothers of medically fragile infants comparing the results of the *Maternal Identity Scale: Critically Ill Infant (MIS)* and *maternal interview rating*. The authors concluded that the scores on the *MIS* correlated with two points on the maternal interviews, namely the mother values being with the infant and the mother views the infant as knowing her (Miles et al., 2011). These findings may suggest that a mother feels more connected and bonded with her infant through performing mothering occupations. One main component to the development of mothering identity has been discussed in the literature is through the process of bonding with the infant (Mercer, 2004).

Through Mercer's (2004) work on the maternal role attainment theory, bonding was discussed as a facilitator to mothering identity. However, Mercer (2004) studied the typical

progression of becoming a mother through a linear process from pregnancy to birth of the infant without consideration of a mother experiencing premature labor and delivery. Premature infants who are considered medically fragile may impose a risk factor to the development of the maternal role and mothering identity (Holditch-Davis et al., 2011). Holditch-Davis et al. (2011) studied 72 mothers of medically fragile infants to determine the quality of parenting during the first year of life. The authors concluded that mothers of medically fragile infants should receive interventions to support the maternal role during admission in the NICU as well as post discharge from the NICU (Holditch-Davis et al., 2011), is suggesting that mothers of premature infants who are considered medically fragile in the NICU have greater support needs for developing a mothering identity.

Premature birth that leads to admission to the NICU interrupts the typical progression of a women's transformation of becoming a mother and the development of mothering identity (Spinelli et al., 2016). A component of mothering identity that occurs during pregnancy is when a mother envisions the life for herself as a mother and the life of her infant (Spinelli et al., 2016). Mothering identity becomes affected with premature birth as the mother is faced with uncertainty of herself as being capable of caring for a fragile infant and the uncertainty of the survival of her premature infant (Spinelli et al., 2016). Under normal circumstances, the progression to motherhood begins with becoming pregnant, delivering the infant, and caring for the infant and is considered a lifelong occupation (Francis-Connolly, 2009; Mercer, 2004). However, mothers of premature infants are often hurled into motherhood, separated from their infant, and unprepared for the medical complications that are associated with preterm birth (Wigert et al., 2010). The separation of mother and premature infant, medical complexity of the infant, and the highly technical medical environment causes feelings of losing the maternal role, increases

stress, and poses a threat to mother-infant bonding (Spinelli et al., 2016). Therefore, premature birth may be considered a risk factor to the development of mothering identity. Mothering identity has been shown to potentially improve developmental outcomes of premature infants (Spinelli et al., 2016) when the mother assumes the role of primary caregiver and nurturer, which in turn improves the bond between mother and premature infant (Mercer, 2004). Bonding is imperative for the mother, so she may feel a long-lasting emotional connection with the premature infant (Sarapat et al., 2017). Similarly, bonding has been linked to increased responsiveness of the mother to the infant (Provenzi et al., 2017). The mother's ability to care for her infant also increases her sense of competency and wellbeing.

Lack of bonding may have detrimental effects on the mother's wellbeing (Cabrera, 2018) as well as the premature infant's overall development (Pineda et al., 2018; Reynolds et al., 2013). Reynolds et al. (2013) studied 81 premature infants in a Level-III NICU and tracked parental visitation, holding, and skin-to-skin care during the hospitalization. The authors noted that the more parental visits and frequency of being held yielded improved neurobehaviors in the premature infants (Reynolds et al., 2013). The early separation of the premature infant and the mother has been reported in the literature to delay a sense of bonding (Spinelli et al., 2016). Spinelli et al. (2016) interviewed 30 mothers of premature infants in the NICU. One of the themes identified was a disconnection the mother felt from the infant, which negatively affected the mother-infant relationship (Spinelli et al., 2016). Decreased bonding has been suggested to have long-term consequences to maternal competence of caring for the premature infant following discharge home from the NICU (Feeley et al., 2016; Heydarpour et al., 2017). Therefore, the authors highlighted the importance of improving the transition to motherhood in the NICU (Heydarpour et al., 2017) as well as facilitating maternal competence of caring for a

premature infant (Feeley et al., 2016). Overall, understanding the occupation of mothering in the NICU is vital to not only mothers but for premature infants as well.

Mothering Occupations

Mothering occupations include activities that mothers engage in that involve the nurturing and caring for children (Francis-Connolly, 2009) and includes co-occupations, such as feeding, clothing, and bathing infants (Fraga et al., 2019). Mothers often engage in multiple occupations outside of caring for children, such as employment, managing the household, caring for other family members, and caring for pets (Klawetter et al., 2019). Balancing mothering occupations with other occupations results in a heavier workload on mothers compared with non-mothers (Avrech Bar et al., 2016). However, mothering occupations have been reported to give one's life meaning and importance (Avrech Bar et al., 2016). Avrech Bar et al. (2016) interviewed 35 working mothers to explore the meaning of occupations that mothers derive from their maternal role. Many of the working mothers discussed the meaning and value they place on mothering occupations (Avrech Bar et al., 2016). Per the authors, the meaning and value the mothering occupations has for the mother is used to satisfy an internal need to fulfill the maternal role (Avrech Bar et al., 2016). However, for mothers of premature infants in the NICU, engaging in mothering occupations is limited due to the fragility of the infants, reliance on medical staff, and the complex medical environment.

Mothering occupations in the NICU are limited not only by the medical complexity of the premature infant and highly technical environment of the NICU but also from interference of medical staff (Fraga et al., 2019). In a meta-ethnographic synthesis, Gibbs et al. (2015) found 35 studies that explored mothering occupations in the NICU. The authors noted that occupational disruption occurs when a premature infant is admitted to the NICU as mothers are reliant on

medical staff to perform the majority of care for their premature infant (Gibbs et al., 2015). However, learning to adapt to the NICU environment, mothers were able to develop partnerships with medical staff and become familiar with the premature infant's medical needs, which improved their ability to perform mothering occupations (Gibbs et al., 2015). Therefore, understanding the importance of mothering occupations and how to support a mother of a premature infant in the NICU becomes vital to mothers, their premature infant, and all medical staff.

Premature Infants and Mothering in the NICU

Family-Centered Care and Mothering

Family-centered care principles have been discussed in the literature for decades. Family-centered care has the ultimate goal of minimizing the long-term negative effects for premature infants in the NICU by supporting family-interactions with the infant and NICU staff (Craig et al., 2015). The goal for integrating families into the care of their premature infant in the NICU was established in response to the prolonged separation of the infant and their mother in order to provide medical care for the infant (Gooding et al., 2011). The ongoing separation of the premature infant and their mothers and families persisted well into the 1960s as infection control measures were placed as the most important aspect of premature infant care (Gooding et al., 2011). However, with the drive for consumer friendly care initiatives in the 1960s to 1980s, hospitals began promoting parenting skills as part of care that sparked ideas of family-centered care (Harrison, 1993). Finally, in 1992, family-centered care was established to advance the concepts of incorporating families for the care of patients (Johnson, 2000). In 1993, the American Academy of Pediatrics featured a special article on the principles for family-centered

neonatal care (Harrison, 1993). The author concluded that families should be the center of all decision making for their premature infant's care in the NICU (Harrison, 1993).

Since then, many organizations have supported family-centered care practices as the gold standard of care in the NICU. Family-centered care has been shown to shorten hospital length of stay, improve mother-infant bonding and attachment, improve developmental outcomes of infants, and improve satisfaction of parents (Davidson et al., 2017; Gooding et al., 2011). One organization, The Institute for Family- and Patient-Centered Care, has published a wealth of information for a variety of medical facilities for the development of family-centered and patient-centered care practices and councils in hopes of providing education on ways to implement family-centered care (Johnson & Abraham, 2012). A specific strategy of the Institute for Family- and Patient-Centered Care is to ensure a family partnership with medical staff to make improvements within the hospital system (Johnson & Abraham, 2012).

Moreover, the National Academy of Medicine has suggested a framework for creating and maintaining a culture of patient- and family-engaged care (Frampton et al., 2017). The authors stated that health care systems should fully integrate the patient and family engaged care framework into the structure and strategy of the hospital organization to ensure implementation at the system level (Frampton et al., 2017). The authors further stated that the creation of a learning culture and structured communication channels facilitates partnerships between families and staff to develop shared goals to support patient and family engaged care (Frampton et al., 2017).

However, despite the evidence and recommendations for implementing family-centered care, many NICUs have failed to incorporate this model of care (Craig et al., 2015). Davidson et al. (2017) discussed practice guidelines for family-centered care in the NICU. The authors stated

hospital staff should train families how to care for their hospitalized infant to improve their competence and confidence in their caregiving role (Davidson et al., 2017). Craig et al. (2015) provided specific recommendations for involvement of the family in the care for their infants in NICUs. The authors stated the family is the most important collaborator in the care for the hospitalized infant (Craig et al., 2015). The authors further presented strategies to support parents, for staff participation, and for NICU policies (Craig et al., 2015).

More specifically, family-centered care in the NICU has been described as a model of care in which the family unit is central in formulating a caregiving plan for the infant (Altimier & Phillips, 2013). Altimier and Phillips (2013) developed seven neuroprotective core measures for family-centered developmental care in the NICU. The authors stated one of most important aspect of caring for premature infants is partnering with the family (Altimier & Phillips, 2013). Mothers play an important role in family-centered care as they can provide breast milk for the premature infant, engage in skin-to-skin care, and participate in mothering occupations, such as bathing and clothing her infant in the NICU (Pierce & Frank, 1992). In a case-report of a mother over a five-year period, Pierce and Frank (1992) highlighted the importance of mother's work for the care of her infant with complex medical needs. The authors emphasized the importance of mothering in the medical world for not only bonding but competence of the mother (Pierce & Frank, 1992). The improved competence of the mother and families as a result of family-centered care may improve premature infant long-term outcomes. Authors have stated that increased family involvement in care results in improved developmental outcomes of premature infants at 4 to 5 years of age (Pineda et al., 2018). The authors studied 81 premature infants born less than 32 weeks' gestation and their families over their hospital length of stay as well as follow up at age 4 to 5 years (Pineda et al., 2018). Family presence in the NICU measured as

visitation days and participation measured by the amount of holding and skin-to-skin care was collected throughout the length of stay (Pineda et al., 2018). The authors noted increased presence and participation yielded improved development at term or 40 weeks' gestation and improved gross motor skills at 4 to 5 years of age (Pineda et al., 2018). Although many researchers have concluded that the family-centered care model should be used in the NICU as it has been shown to reduce hospital length of stay and reduce readmission to the hospital (Mirlashari et al., 2019), barriers for implementation are still prominent (Gibbs et al., 2016).

Barriers to family-centered care in the NICU have been identified and discussed by researchers in the literature. In a qualitative study, authors interviewed 11 nurses who identified challenges to implementing family-centered care (Mirlashari et al., 2019). The challenges were taking on multiple roles as a nurse, feeling judged by parents, having difficulty trusting parents to perform tasks correctly, and becoming involved in the personal lives of the families (Mirlashari et al., 2019). The authors reported nurses may not feel supported by hospital policies for implementing family-centered care (Mirlashari et al., 2019). Hence, the authors stated hospitals should invest in family-centered care principles as the gold standard of care, which would provide educational programs and training for staff (Mirlashari et al., 2019), which in turn would support a culture and practice change driven by nursing and medical staff (Mirlashari et al., 2019). Support for culture changes is also discussed in the patient and family engaged care framework put forth by the National Academy of Medicine to overcome barriers for the support of families at the system level (Frampton et al., 2017). Overall, the hospital system has a role in cultivating an environment for the support of all families in the care for their premature infant in the NICU.

Per the Occupational Therapy Practice Framework (OTPF), 4th edition, *context* can be described as an extensive concept that comprises both environmental factors and personal factors (AOTA, 2020). The environmental factors related to family-centered care in the NICU may involve *products and technology*, *support and relationships*, *attitudes*, and *services, systems, and policies* (AOTA, 2020). Examples of how the environmental factors of the NICU may pose as a barrier would be the lack of space for mother's to perform breast milk expression, limited space and furniture to perform skin-to-skin care, and inability to sleep at the bedside (Hernández et al., 2016). Additionally, despite the evidence of the benefits of family-centered care, prolonged hospitalization of premature infants limits the time mothers and families can be present at the bedside due to a plethora of circumstances such a distance from the hospital, care of other children at home, returning to work, and financial strain (Gibbs et al., 2016; Pineda et al., 2018).

Personal factors of the mothers that should be recognized when implementing family-centered care in the NICU, which include her *age, gender identity, race and ethnicity, cultural identification and cultural attitudes*, *social background, social status, socioeconomic status*, *upbringing and life experience*, and *education* (AOTA, 2020) to name a few. When a mother cannot be at the bedside of her premature infant due to social circumstances outside of her control, the benefits of family-centered care are lost to her (Pineda et al., 2018; Reynolds et al., 2013; Wigert et al., 2010). In a quantitative study of 81 premature infants in the NICU, the authors identified more parental presence among mothers who were Caucasian, married, older, employed, had fewer children at home, had familial support, and provided breast milk for the premature infant (Pineda et al., 2018). There is limited literature in which researchers explored the experience of mothers of premature infants in the NICU who are from a variety of cultural

backgrounds, which may affect their perception of medical care, their experience in the hospital, and their relationship with the medical staff (Al Maghaireh et al., 2016; Gibbs et al., 2016).

Although family has been identified as the most important aspect of family-centered care in the care of premature infants (Altimier & Phillips, 2013; Craig et al., 2015; Davidson et al., 2017), recognizing each family's culture and the importance of honoring their culture may be lost in the medical setting of the NICU. Cultural humility has been defined in the literature as an approach to working with individuals with a plethora of cultural backgrounds and an acknowledgement of the power dynamics that exists in health care settings (Tervalon & Murray-Garcia, 1998). Cultural humility includes the need for ongoing learning, identification of gaps of knowledge without indignity, anticipation of differences between cultures, recognitions of implicit and explicit bias of individuals, and endorsement a positive change based on identified bias (Agner, 2020). Cultural humility has a requirement for a shift of realizing individuals are culturally different from the occupational therapist or health care professional to understanding that cultural differences are a part of the therapeutic relationship (Hammell, 2013). Hence, cultural humility has a requirement for dedication to critical self-reflection to identify bias and rectify any power imbalances that lie between the therapist or health care professional and patient (Hammell, 2013). Cultural humility accentuates The importance of how individuals place value on their perceived cultural lives and how individuals experience any inequalities in society is accentuated by cultural humility, which both affect their occupations and a sense of well-being (Hammell, 2013). There is an academic gap in the literature exploring cultural humility in the NICU as well as cultural humility in family-centered care. Other authors have stated a gap in the literature exists in understanding parental visitation barriers (Latva et al., 2007) and parental participation in bedside care with their premature infant (Gonya & Nelin,

2013). Overall, family-centered care has been stated as the gold standard of care for the premature infant in the NICU.

The Neonatal Intensive Care Unit

Over the past century, there have been many advances to medical care in the NICU. In the US, NICU care was first established in the early 1900s (Jorgensen, 2010). The first incubator was developed in the late 1890s by French neonatologist Dr. Tarnier, which was modeled after a hen incubator (Jorgensen, 2010). Dr. Tarnier was credited for bringing the incubator to the US for the care of premature infants (Mazurak & Czyżewska, 2006). However, in the US, premature infants in incubators were often part of circus shows until the 1940s (Mazurak & Czyżewska, 2006). Then in the late 1950s, Virginia Apgar developed the Apgar scores to evaluate newborns (Jorgensen, 2010). Another advancement to neonatal care was the use of surfactant to assist in respiratory function (Jorgensen, 2010). By the 1950s, the World Health Organization and the American Academy of Pediatrics both defined prematurity by an infant's birth weight (Jorgensen, 2010). Currently, prematurity is classified by completed weeks of gestation (World Health Organization, 2018).

Over the past 100 years, many advancements have been made to the NICU environment, including training of medical staff and inclusion of families for the care of the premature infant. There are four levels of NICU care as stated by the American Academy of Pediatrics in the *Guidelines for Perinatal Care, 8th Edition* (American Academy of Pediatrics, 2017). The type of medical care is determined by the facility's ability to medically intervene from a surgical and respiratory level (American Academy of Pediatrics, 2017). A Level 1 NICU has been classified as a wellborn nursery, whereas a Level II NICU can provide more specialized care, such as blood transfusions and medical care for resuscitation (American Academy of Pediatrics, 2012). A

Level III NICU has been stated as a facility that can medically and surgically intervene for premature infants born less than 32 weeks' gestation (American Academy of Pediatrics, 2012). A Level IV NICU has been defined as a regional neonatal intensive care unit, which has surgical intervention and lifesaving medical care to infants born less than 32 weeks' gestation and weighing less than 1500 grams (American Academy of Pediatrics, 2012). A Level IV NICU is considered to be the highest level of medical care and is able to provide surgical interventions for complex congenital or acquired medical conditions (American Academy of Pediatrics, 2012). A Level IV NICU environment consists of highly technical equipment, loud noises, bright lights, and a plethora of medical staff (Ross et al., 2017).

The medical staff in a Level IV NICU consists of an interdisciplinary team (Barbosa, 2013), which includes neonatologists, general surgeons, ophthalmologists, pulmonologists, gastroenterologist, cardiologists, orthopedics, respiratory therapists, nurses, occupational therapists, physical therapists, speech therapists, audiologists, child life specialists, pastoral services, parent educators, and social workers (Vergara & Bigsby, 2004). Ross et al. (2017) identified patterns of neonatal therapy (occupational therapy [OT], physical therapy [PT], and speech therapy [ST]) usage in a Level IV NICU and concluded that occupational therapy services are vital to the developmental outcomes and occupational performance of premature infants. The authors further stated that occupational therapy services were the only service that focused on upper extremity functioning and visual development (Ross et al., 2017). Mothering is supported by occupational therapists in the NICU as well. Per the AOTA (2018), occupational therapists are able to evaluate and treat the occupational skills of the family for the support of the infant from admission to discharge from the NICU. Therefore, occupational therapy can be stated as a fundamental service for the care of premature infants and their mothers in the NICU.

Developmental Care and Mothering

The premature infant and how they develop from a neurological and sensory perspective was taken into consideration when developing the synactive theory (Als, 1982). Als (1982) discussed the importance of understanding infant development when working with premature infants in the NICU. Based on Als' synactive theory, a clinician can develop an individualized plan of care for the premature infant to ensure optimal neurodevelopment (Als, 1986). Protecting the premature infant from the harsh environment of the NICU in turn promotes neurodevelopment and minimizes the morbidity of prematurity (Als, 1982). Als (1982) stated that parents and medical staff can understand an infant by reading their cues, which provides information of the premature infant's strengths and areas for support as the infant grows (Als, 1986). Als' seminal work with premature infants has paved the way for developmental care practices to be implemented by medical staff in the NICU.

As premature infants continue to be resuscitated at earlier gestational ages, protection of their neurodevelopment becomes more important to reduce morbidities and improve long-term developmental outcomes (Gibbins et al., 2008). Gibbins et al. (2008) expanded the ideas of Als' synactive theory and created the universe of developmental care (UDC). UDC is used to highlight the importance of the mother-infant relationship, the NICU environment, and medical staff when caring for the premature infant (Gibbins et al., 2008). UDC has a systematic way of assessing developmental care from all components of its model versus solely relying on infant behavioral cues (Gibbins et al., 2008).

Many authors have further expanded the concepts and ideas of UDC and Als' synactive theory in formulating models of care for the NICU, such as core measures for developmentally supportive care by Coughlin et al. (2009) and the neonatal integrative developmental care model

by Altimier and Phillips (2013). Coughlin et al. (2009) discussed five core measures for developmental care in the NICU, which included (a) protected sleep, (b) pain and stress assessment and management, (c) developmental activities of daily living, (d) family-centered care, and the healing environment (pp. 2242-2244). Throughout each core measure, there are opportunities for mothering occupations that can be facilitated. Mothers can be educated about how to promote sleep by performing skin-to-skin care, swaddled bathing, and facilitated tuck (Coughlin et al., 2009). Mothers can also provide support to the infant during painful procedures and to calm the infant when experiencing stress, such as providing skin-to-skin care, maternal milk scented cloths, and infant massage (Coughlin et al., 2009). Mothering occupations are evident in developmental activities of daily living as the focus is on infant feeding, positioning, and skin-to-skin care (Coughlin et al., 2009). In the family-centered care measure, Coughlin et al. (2009) stated that families have unrestricted access to their infant, family competence and confidence should be facilitated, and families should be supported through resources. Mothering occupations, such as feeding, diapering, clothing, skin-to-skin care, and infant massage, are fully supported in the family-centered care measure (Coughlin et al., 2009). Light and noise levels are taken into consideration in the healing environment, collaboration between health care providers, and hospital policies and resources for developmental care practices as standard of care (Coughlin et al., 2009). Similar to Coughlin's core measures of developmentally supportive care, Altimier and Phillips (2013) developed the neonatal integrative developmental care model.

The neonatal integrative developmental care model has been defined as an integrative approach for providing care for premature infants in the NICU that has foundational knowledge on neuroprotection, developmental care, and sensory integration (Altimier & Phillips, 2013). The seven core measures of the neonatal integrative developmental care model include (a)

healing environment, (b) partnering with families, (c) positioning and handling, (d) safeguarding sleep, (e) minimizing stress and pain, (f) protecting skin, and (g) optimizing nutrition (Altimier & Phillips, 2013, pp. 12-17). In the healing environment, Core Measure 1 includes not only the physical environment of the NICU, such as space, privacy, and safety, but also the sensory environment, such as light, noise, temperature, and the tactile, vestibular, olfactory and gustatory systems of the infant (Altimier, 2015). The focus of mothering occupations to support the healing environment of the premature infant should be on positive sensory experiences, such as providing maternal scent cloths, oral care with breast milk, infant massage, and skin-to-skin care (Altimier, 2015).

The focus of Core Measure 2 includes partnering with families for the inclusion of the family in all aspects of care for the premature infant. Mothers should be encouraged to participate in medical rounds, educated on infant cues, and included in all aspects of infant care at the bedside to improve maternal competence in the care of her infant (Altimier & Phillips, 2013). Core Measure 3 is positioning and handling (Altimier & Phillips, 2013). Premature infants require therapeutic positioning outside of the womb to promote neuromotor development (Altimier & Phillips, 2013). Therapeutic handling also reduces stress in the premature infant by facilitating a tucked position and containment for calming (Altimier & Phillips, 2013). The mothering occupation of skin-to-skin holding not only achieves therapeutic positioning but also therapeutic handling as the premature infant is able to maintain a tucked and flexed position with total body containment on the mother's chest (Altimier & Phillips, 2013). Safeguarding sleep, which is Core Measure 4 is an important core measure as optimal brain healing and growth occurs during deep sleep (Altimier & Phillips, 2013). Mothers can be educated about protecting

the premature infant's sleep but also about developmental care strategies to reduce stress during mothering occupations (Altimier & Phillips, 2013).

Core Measure 5 is about minimizing pain and stress in the premature infant by providing developmental care strategies during routine infant care (Altimier & Phillips, 2013). Typical mothering occupations can be perceived as stressful to the premature infant, such as changing a diaper, bathing, and dressing (Altimier & Phillips, 2013). Supportive strategies for the premature infant, such as swaddled bath, containment in flexion, and reducing environmental stimulation, reduces stress and energy expenditure (Altimier & Phillips, 2013) and should be incorporated in mothering occupations. Strategies and care methods for protecting skin, which is Core Measure 6, should be considered at each gestational age of development (Altimier & Phillips, 2013). Premature infant's skin is fragile and thin (Altimier & Phillips, 2013). Mothering occupation of bathing and lotion massage should be carefully implemented at the correct gestational age to prevent adverse events, such as hypothermia and skin breakdown or tears (Altimier & Phillips, 2013). Optimizing nutrition is Core Measure 7 and includes the importance of breastfeeding or providing breast milk for the nutritional intake of the premature infant (Altimier & Phillips, 2013). Mothering occupations, which support optimizing nutrition, include skin-to-skin holding, infant-driven feeding whether by breast or bottle nipple, and expression of breast milk for tube feedings (Altimier & Phillips, 2013). Overall, the authors concluded that implementing the 7 core measures in the NICU not only improves the outcomes of the premature infant but improves satisfaction of families (Altimier & Phillips, 2013).

In a systematic review of developmental care in the NICU, 19 articles were reviewed, which showed that developmental care improves premature infants' language, motor, and cognitive development (Burke, 2018). Developmental care was also discussed as improving

maternal competence, well-being, and maternal health (Burke, 2018). With the key findings in the study, Burke (2018) also highlighted the importance of early intervention, holding, touching, and parent involvement for improved neurodevelopmental outcomes of the premature infant. Early involvement of the mother in providing care to the premature infant has resulted in improved neurodevelopment of the premature infant (Pineda et al., 2018). Therefore, developmental care practices should incorporate the mother for optimal developmental outcomes for the premature infant.

Regardless of the theory, model, or core measures, all developmental care practices are supporting the neuroprotection of the premature infant as well as positive mother-infant interaction. Educating the mother about the premature infant's sensory development and the premature infant's needs at each gestational age also promotes positive mother-infant interaction (Pineda et al., 2019). Pineda et al. (2019) developed a sensory-based intervention program for specific postmenstrual ages to provide positive sensory experiences for the premature infant. Pineda et al. (2019) utilized knowledge obtained from Als' synactive theory, developmental care, and family-centered care when developing the sensory-based intervention program. The sensory-based intervention program also is used to educate the mother about ways to positively and safely interact with her premature infant based on gestational ages (Pineda et al., 2019). Although the sensory-based intervention program has not been studied extensively, the aim of the program is to increase parental involvement and improve developmental outcomes of the premature infant.

In current NICU practice, family-centered developmental care practices are used by medical staff to ensure inclusion of the mother into the care for her premature infant (Craig et al., 2015). By combining the principles for both family-centered care and developmental care,

family-centered developmental care shows the importance of neuroprotection of the premature infant (Altimier & Phillips, 2013). Neuroprotective care is described as protecting the developing brain of the premature infant by adapting the environment and modifying caretaking strategies, such as clustering care (Altimier & Phillips, 2013). By adapting the environment, sensory input can be lessened to protect the premature infant, such as reducing light and noise levels (Altimier, 2015). Clustering care can limit the number of times the premature infant is handled and reduces interrupted sleep (Coughlin et al., 2009). Deep sleep is important for the premature infant as it facilitates brain development and improves weight gain (Coughlin et al., 2009). Overall, family-centered developmental care has been shown as the facilitator of family involvement, which has long lasting effects on the premature infant's development (Craig et al., 2015)

There is a gap in the literature about exploring the parents' experience of family-centered developmental care (Obeidat et al., 2009), finding efficient ways of educating all parents in family-centered developmental care (Burke, 2018), and exploring the needs of parents to ensure parental involvement in family-centered developmental care (Skene et al., 2019). Overall, when providing family-centered developmental care, the mother should be included in all aspects of care for the premature infant, which ensures not only optimal developmental outcomes for the premature infant but also the health, well-being, and competence of the mother.

Premature Infant and Mothering

A premature infant is a neonate born alive less than 37 weeks' gestation (World Health Organization, 2018). Gestational age is determined by the number of completed weeks of pregnancy since conception or a woman's last menstrual period (American Academy of Pediatrics, 2004). Per the World Health Organization (2018), premature infants are considered moderate to late preterm when born between 32- and 37-weeks' gestation and very preterm when

born between 28- and 32-weeks' gestation. Premature infants are defined as extremely preterm when born less than 28 weeks' gestation (World Health Organization, 2018). Many infants born extremely premature at less than 28 weeks' gestation require medical care in a Level IV NICU and often face prolonged hospitalization (Pineda et al., 2018). Medical advances in neonatal care have paved the wave for resuscitation of premature infants as early as 22 weeks' gestation, which correlates to prolonged hospitalization over many weeks and months in the NICU (Altimier & Phillips, 2013). Prolonged hospitalizations may have long-term developmental implications for the premature infant (Baum et al., 2012; Neu et al., 2013; Provenzi et al., 2017). Therefore, understanding premature infants born less than 28 weeks' gestation and the impact on the mother is vital for optimal long-term outcomes.

Premature infants who are born extremely preterm or less than 28 weeks' gestation are at the greatest risk for experiencing developmental delays (Russell et al., 2014). Extreme prematurity often requires immediate life-saving measures, which separates the infant and the mother directly following birth (Raiskila et al., 2017). The necessary separation between the mother and her premature infant due to medical interventions may cause a boundary to mother-infant bonding and attachment (Pineda et al., 2018; Pineda et al., 2019). Authors have stated the need for programs in the NICU to minimize separation of the mother from the infant (Feeley et al., 2016), promote visitation (Greene et al., 2015), and improve the quality of the parent-infant relationship (Franck & Spencer, 2003).

Infants who are born premature have underdeveloped brains, body systems, and body functions, which places them at a higher risk for long-term developmental delays (Altimier & Phillips, 2013). Understanding brain development, gestational development, and emotional development of premature infants is at the center of neonatal care (Altimier & Phillips, 2013).

Protection of the premature brain is often referred to as neuroprotection in which strategies are implemented to prevent brain cell death and to promote neuroplasticity (Altimier & Phillips, 2013). Each sensory system forms at certain gestational ages in utero, and this knowledge should be incorporated in care strategies for premature infants in the NICU (Graven & Brown, 2008). Graven & Brown (2008) discussed how premature birth may accelerate organ system development, such as the lungs, but does not accelerate the developmental progression of neurodevelopment. Therefore, protective measures for the developing neurosensory systems must be provided to the premature infant to reduce co-morbidities of being born premature (Graven & Brown, 2008).

Graven and Brown (2008) further discussed how the NICU environment produces a stress response in premature infants, which causes an iatrogenic impact to neurodevelopment. Furthermore, sensory exposure at the wrong intensity and at the wrong gestational age lead to altered brain development (Graven & Brown, 2008). The authors concluded that the care of premature infants should include a developmentally supportive environment as well as developmentally appropriate care practices (Graven & Brown, 2008). Emotional development in the premature infant begins with mother-infant relationship and attachment (Korja et al., 2012). The authors completed a systematic review of studies related to early mother-infant relationships in the NICU in which 29 articles met inclusion criteria (Korja et al., 2012). The authors concluded that improving mother-premature infant relationships were the result of decreasing maternal stress and decreasing early separation of the mother and premature infant (Korja et al., 2012).

Korja et al. (2008) focused on the amount of holding and its influence on the mother-infant relationship. The authors noted increased holding of the premature infant by their mother

correlated to improved mother-infant relationships at 6 months and 12 months of age (Korja et al., 2008). The emotional development of the premature infant also appeared to be influenced by visitation patterns of the mother (Latva et al., 2004). The authors studied 67 premature infants and completed a follow-up assessment at age 7 years to 8 years and noted more behavioral and emotional disorders in the participants whose mothers visited infrequently (Latva et al., 2004). Therefore, the model of care that improves the long-term outcomes of premature infants is focused on how the premature infant communicates and has strategies to support the premature infant is known as family-centered developmental care or neuroprotective care (Altimier & Phillips, 2013; Burke, 2018; Butt et al., 2013; Coughlin et al., 2009; Heermann et al., 2005; Hernández et al., 2016). Using the family-centered developmental care model, occupational therapists have the opportunity to support mothering of premature infants in the NICU.

Occupational Therapy and Mothering

Working within the interdisciplinary team, the occupational therapist contributes to the care of the premature infant and family (Ross et al., 2017). The occupational therapists in the NICU utilize their knowledge of typical development of infants and collaborates with families and staff in order to provide family-centered care and developmental care (American Occupational Therapy Association, 2018). In a quantitative study of 79 premature infants in a Level IV NICU, Ross et al. (2017) determined that 100% of the premature infants received occupational therapy services. The authors showed that part of the services the occupational therapists provided included family education and training (Ross et al., 2017). The authors also found that occupational therapy services included infant behavioral organization, developmental care, neurodevelopment, positioning, sensory motor activities, and optimizing occupational

participation (Ross et al., 2017). Occupational therapy not only addresses the premature infant's occupational needs but also the premature infant's mother's occupational needs.

In a multiple case study report, Fraga et al. (2019) discussed the occupational therapist's role in promoting mothering occupations and co-occupations with her infant. The occupation of mothering is affected when an infant is admitted to the NICU due to the medically complex environment (Gibbs et al., 2010). Mothers often feel as though the caregiving tasks are taken over by medical staff due to the fragility of the infant (Gibbs et al., 2010). Mothering occupations may be hindered in the NICU environment due to the highly technical equipment (Gibbs et al., 2016). Additionally, Gibbs et al. (2016) stated that mothers often feel as though there is a communication breakdown with the staff, which interferes with opportunities for caregiving.

Opportunities for mothering occupations are often limited in the NICU environment, which can lead to feelings of vulnerability and a loss of maternal control (Woodward et al., 2014). Woodward et al. (2014) studied 133 mothers of premature infants in a Level III NICU. The authors found that the majority of stress mothers experienced was a direct result of losing the perceived maternal role (Woodward et al., 2014). Recommendations to overcome maternal stress (Woodward et al., 2014), loss of maternal role (Holditch-Davis et al., 2011), and inclusion of mothers in care (Gibbs et al., 2016) have been stated in the literature as family-centered care. Therefore, it is critical for occupational therapy services in the NICU to incorporate family-centered developmental care to ensure a mother's involvement in all aspect of care for her premature infant.

Theoretical Perspectives

Person-Environment-Occupation Model

The person-environment-occupation (PEO) model is a transactive approach to understanding occupational performance (Law et al., 1996). The PEO model was designed for use by occupational therapists as a guide for considering a person's abilities, preferred occupations, and the environments in which they will be participating in occupations (Dunbar, 2007). There are three components to the PEO model, which are the person, the environment, and occupation (Law et al., 1996). The PEO model is depicted by three linked circles in which the overlap among the circles represents occupational performance (Dunbar, 2007). Occupational performance often changes across the lifespan when variations in person, environment, and occupation are evident (Law et al., 1996). The major concepts of the PEO model include (a) the person; (b) the environment; (c) activity, task, and occupation(s); and (d) occupational performance (Law et al., 1996, pp. 15-16).

Per Law et al. (1996), the person is defined as one who encompasses specific characteristics and holds a variety of roles. The specific characteristics of the person are often unique such as spiritual, cognitive, emotional, and physical attributes (Law et al., 1996). The person also includes personality styles, cultural influences, and self-concept (Law et al., 1996). Other considerations for the person are factors like overall health and well-being (Law et al., 1996). Law et al. (1996) stated that a person utilizes their set of skills to participate in occupational performance. In an expert opinion paper, Gibbs et al. (2010) applied the PEO model to assist in understanding parenting occupations in the NICU. The authors stated the person could be considered the premature infant or the mother when applying concepts of PEO in the NICU (Gibbs et al., 2010). Considerations of the premature infant would center around their limited capabilities to engage in the NICU environment (Gibbs et al., 2010). The limited capabilities of the premature infant often results in a mother having a difficult time interacting or

caring for them in a typical manner (Gibbs et al., 2010). Subsequently, the mother may experience stress, fear, and feelings of a loss of the maternal role (Holditch-Davis et al., 2015).

The environment is described by Law et al. (1996) as a broad term, which includes aspects like the physical, social, cultural, socio-economic, and institutional considerations. The meaning of the environment is determined by the perspective of each person, household, community, or group (Dunbar, 2007). Another consideration is that environments often influence behavior (Law et al., 1996). Gibbs et al. (2010) discussed the environment of the NICU consisted of not only the physical environment, such as lighting, medical equipment, and the design of the unit, but also the medical staff with whom the mothers interact with during the hospitalization of their premature infant. The physical environment of the NICU imposes significant stress for the premature infant as well as their mothers (Gibbs et al., 2010). The bright lights, loud noises, excessive handling by multiple staff members, and invasive procedures all impose stress responses of the premature infant (Gibbs et al., 2010). The authors reported that the NICU environment poses a barrier to performing mothering occupations as the highly technical medical equipment is intimidating and the medical staff are viewed as gatekeepers to the premature infant (Gibbs et al., 2010). Collaboration between medical staff and the premature infant's mother was recommended by Gibbs et al. (2010) to facilitate mothering occupations and maternal role development.

Activity, task, and occupations were described as directly relating to one another as one concept by way of the term occupation (Law et al., 1996). Occupation is detailed by Law et al. (1996) as "groups of self-directed, functional tasks and activities in which a person engages over the lifespan" (p. 175). Occupation is a way for a person to meet intrinsic needs for life fulfilment, self-expression, and self-maintenance (Law et al., 1996). Occupations are performed within the

context of individual roles and the individual's environments (Law et al., 1996). Mothers of premature infants have difficulty performing mothering occupations in the NICU due to the medical status of the infant and the highly technical environment of the NICU (Gibbs et al., 2010). The unanticipated event of having a premature birth alters the typical ritual a mother experiences of delivering the infant, taking the infant home from the hospital, and having a welcome-home congratulations from family and friends (Gibbs et al., 2010). This alteration of a normal pregnancy and delivery often interferes with the progression into motherhood and the mothering identity (Holditch-Davis et al., 2011). Due to the medical complexity of the infant and the technical medical environment of the NICU, mothers experience a loss of the maternal role in which mothering occupations, such as bathing, feeding, and dressing their premature infant, are often performed by medical staff (Gibbs et al., 2010). Therefore, Gibbs et al. (2010) suggested a focus on mothering occupations to improve their competence and confidence in caring for their premature infant.

Occupational performance is described as the outcome of the transaction between the person, the environment, and the occupation (Law et al., 1996). Occupational performance is further described as a dynamic process, which occurs when a person is engaged in occupations within their environment (Law et al., 1996). Occupational performance is also considered by patterns of engagement over a time period (Dunbar, 2007). Occupational performance of the mother may be limited by the NICU environment, medical staff, and medical status of the premature infant (Gibbs et al., 2010). These barriers to occupational performance result in a person-environment discrepancy, which causes an imbalance to the person (Gibbs et al., 2010).

There are assumptions about the PEO model for each of the components and the interactions between the components (Law et al., 1996). The assumptions about the person is that

they are a dynamic, motivated, evolving individual who is interacting within the environment (Law et al., 1996). The assumptions about the environment is that it is an ever-changing place in which occupations occur, it influences behavior, and can be enabling or interfering with occupational performance (Law et al., 1996). The assumptions about occupations is that they meet the person's needs, have a purpose, are complex, and are necessary for functioning throughout life (Law et al., 1996). The assumptions in regard to occupational performance is that it is a multifaceted and dynamic phenomenon, which has a temporal aspect (Law et al., 1996). Occupational performance is further assumed as being formed by the transaction between the three components, the person, the environment, and occupation (Law et al., 1996). The final assumption refers to the person-environment-occupation fit (Law et al., 1996).

The person-environment-occupation fit of the PEO model has an assumption that the person, environment, and occupation interact continuously throughout time and space, which either increases or decreases their congruence (Law et al., 1996). Optimal occupational performance is, therefore, determined when more overlapping of the three components is evident or there is a maximizing of fit (Law et al., 1996). Conversely, lack of fit or minimizing of fit occurs when there is less overlapping of the three components (Law et al., 1996). Therefore, Law et al. (1996) suggested occupational therapists should improve the abilities of the person, enable aspects of the environment, and adapt the occupation when able to improve occupational performance.

Gibbs et al. (2010) analyzed the NICU using the PEO model to explore decreased parental occupational performance. The authors discussed the transactions between the occupation-environment, the person-environment, and the person-occupation of the parent of premature infants in the NICU (Gibbs et al., 2010). When discussing the occupation-

environment transaction, the authors discussed barriers for occupational performance, such as medical equipment and medical support the premature infant required (Gibbs et al., 2010). The person-environment transactions were described as barriers to occupational performance when hospital visiting policies did not allow for 24-hour visitation, distance from the hospital prohibited parental presence, medical staff assuming the caregiving role, and poor communication patterns between staff and parents (Gibbs et al., 2010). Currently, best practice in the NICU is to allow for 24-hour access to infants for all parents, which improves parent and staff partnerships (Frampton et al., 2017). Finally, the person-occupation transactions were noted as being a barrier to occupational performance when the fragile infant's medical status needs medical management during caregiving, decreased opportunities for engagement in caregiving, feelings of inadequacy of the parent, and fearful of harming the infant (Gibbs et al., 2010). The authors stated that despite family-centered developmental care being noted as the gold standard of care in NICUs, poor implementation of this model remains rampant, therefore, utilizing an occupation-based model of care, such as PEO would increase and support occupational performance of mothers of premature infants (Gibbs et al., 2010).

An Occupational Theory of Human Nature

An occupational theory of human nature is founded on the belief that humans have an inborn need to participate in occupations (Wilcock & Hocking, 2015). Occupation is defined as: (a) the things that humans do; (b) the relationship between the things that humans do and how that defines the human; and (c) by doing occupations, the human is in a state of becoming different (Wilcock & Hocking, 2015, pp. 117-140). The inborn need is supported by the brain's structure and physiology, which drives occupational behavior (Wilcock, 1993; Wilcock, 2006; Wilcock & Hocking, 2015). The survival of humans is solely established by the primary function

of human's biological characteristics, which have evolved over time (Wilcock & Hocking, 2015). The human brain uses occupation as the primary means of supporting survival, facilitating health, and supporting a sense of well-being (Wilcock, 2006). Moreover, the human's ability to use dexterity has support for the use of occupations for health and well-being (Wilcock & Hocking, 2015). Wilcock & Hocking (2015) discussed how humans evolved over time to use bipedal gait and upright posture, stereoscopic vision, and complex language all which are directly related to survival, health, and well-being.

The environment has an important role in the occupational theory of human nature. Wilcock and Hocking (2015) stated that the engagement in occupation has a direct effect on the physical and social environment. Furthermore, occupation gives way for human survival and the ability to adapt to biological, political, sociological, and environmental circumstances (Wilcock & Hocking, 2015). Therefore, the ability to perform occupations in environments either known or foreign to humans has support for survival, health, and well-being (Wilcock & Hocking, 2015).

Wilcock and Hocking (2015) postulated that with an occupational theory of human nature, there is a three-way link between occupation, health, and survival of humans (Wilcock & Hocking, 2015). The ability to engage in occupations is directly related to the health of the human in the areas of energy, drive, and functional characteristics, which are required for participation in occupation (Wilcock & Hocking, 2015). Also, the survival of humans as a healthy species is one that requires one to live in unity with others in an environment that can offer basic needs (Wilcock & Hocking, 2015). However, the environment is often outside of the humans control, such as the social, economic, and physical environments (Wilcock & Hocking, 2015). The human's characteristics, attributes, and behaviors are important considerations when

viewing the ability to engage in occupations in differing environments (Wilcock & Hocking, 2015). Consequently, humans are viewed as occupational beings who give importance to occupations through four concepts: doing, being, belonging, and becoming (Wilcock, 1993; Wilcock, 2006; Wilcock & Hocking, 2015, pp. 134-140). These concepts are emphasized by the human's ability to engage in occupations that are culturally situated and are influenced by the available resources, socioeconomical constraints, political contexts, gender expectations, and historical patterns (Wilcock & Hocking, 2015).

The meaning that is attached to occupations is determined by doing, being, belonging, and becoming (Wilcock & Hocking, 2015). In a qualitative study exploring the experiences of 23 adults with life-threatening illnesses, Lyons et al. (2002) found that applying the concepts of doing-being-becoming highlighted the importance of occupational engagement to wellbeing. The authors found that focusing on the occupations that the participants could perform instead of the ones they could no longer perform as a result of their illness increased their sense of well-being (Lyons et al., 2002). In comparison to the Lyons et al. (2002) study, mothers of premature infants also experience how life-threatening illness of their premature infant impacts their participation in caregiving occupations, which has a direct link to feelings of well-being (Gibbs et al., 2016). Engagement in occupation gives a sense of meaning and purpose to humans (Wilcock & Hocking, 2015) and the meaning assigned to the occupation often gives an individual a sense of place in their social and physical environment (Horne et al., 2005)

Doing has been described as an action of accomplishing a task or activity (Wilcock & Hocking, 2015). The inborn need for doing is unique to humans and the engagement of doing involves tasks that need to be done and want to be done (Horne et al., 2005). Mothering occupations can be considered action-based caregiving activities and tasks that a mother

completes for the overall development of her infant (Francis-Connolly, 2009). In the NICU, many of the caregiving tasks are often performed by medical staff, which acts as a barrier to the doing of mothering occupations (Russell et al., 2014). Therefore, an occupational therapist should facilitate the doing of occupations for the premature infant by the mother instead of the medical staff (Gibbs et al., 2010), which would in turn allow for the doing of mothering occupations for the premature infant in the NICU by the mother (Gibbs et al., 2016). In a qualitative study, Avrech Bar et al. (2016) interviewed 35 women who discussed the need for doing mothering and nonmothering occupations for the reward and appreciation the mothers need, which affirms the internal drive humans have for doing occupations for mind and body health and well-being. Furthermore, doing has been identified as the enabler for the concept of being (Wilcock & Hocking, 2015). Therefore, the doing of mothering occupations for the premature infant may support a sense of being in the NICU.

Being was described as the time a human spends in reflecting on the past, present, and future (Wilcock & Hocking, 2015). Mothers in the NICU may have increased stress that has the potential to affect a mother's ability to have positive views of her and her infant's past, present, and future (Greene et al., 2015). Being has been described as facilitating a sense of well-being (Wilcock & Hocking, 2015). A mother's capability for doing mothering activities and tasks for her premature infant may also improve her sense of well-being (Reynolds et al., 2013). Mothers have reported that being a mother is meaningful, is a valued occupation, and is a vital necessity for a woman's life (Avrech Bar et al., 2016). Therefore, supporting the mother at the infant's bedside and guiding the mother in performing occupations will allow for a positive sense of being in the NICU (Gibbs et al., 2016). Likewise, the engagement in mothering occupations may

improve the feeling of belonging in the medically complex environment of the NICU (Sarapat et al., 2017).

Belonging has been described as being associated with others, places, and things (Wilcock & Hocking, 2015). Feelings of belonging are often related to being associated with something or someone, being in the right place, or feelings of attachment (Wilcock & Hocking, 2015). Furthermore, an individual ascribes meaning to life experiences through belonging (Avrech Bar et al., 2016). Avrech Bar et al. (2016) discussed how mothers place meaning on mothering occupations and how a sense of belonging affects the maternal role. The NICU may be perceived as an overwhelming environment for mothers to learn how to perform mothering occupations for their premature infants (Gibbs et al., 2016). Feelings of being overwhelmed may affect their view of belonging in the highly specialized and medical context (Greene et al., 2015). A poor sense of belonging has been stated as a barrier to presence and participation in the NICU (Reynolds et al., 2013). Participation in mothering occupations may alleviate feelings of stress and being overwhelmed, which will allow for a greater sense of belonging in the NICU (Woodward et al., 2014). Belonging in the NICU often has support for bonding between not only the mother and her infant but also developing a relationship between the mother and the medical staff. Mothers often rely on nursing staff for ongoing support during such a traumatic time in their lives (Heermann et al., 2005). The relationship that is formed between mother and nurse is often long-lasting and improves a sense of belonging in the NICU (Heermann et al., 2005). Therefore, when a mother feels supported in the care for her premature infant, the realization of becoming a mother may become apparent (Widding & Farooqi, 2016).

Becoming has been stated as the process of transformation, maturation, and the realization of one's potential (Wilcock & Hocking, 2015). Becoming a mother has a requirement

for a shift in occupational identity, which is everlasting in a woman's life (VanderKaay, 2016). Becoming a mother also involves performing occupations that are new, unfamiliar, and difficult (Horne et al., 2005). Additionally, becoming a mother in the NICU has unique challenges, such as having feelings of inadequacy, prolonged separation from the infant, feelings of guilt, and leaving the caregiving to medical staff (Lundqvist et al., 2019). The sense of becoming a mother may be delayed due the early separation of the premature infant from the mother coupled with feelings of losing control and exclusion in the care of their infant (Obeidat et al., 2009). The sense of becoming a mother may also be affected from the potential of a prolonged hospitalization of the premature infant (Korja et al., 2012). Becoming a mother of a premature infant in the medically complex context of a NICU is a complicated and fragile process (Gibbs et al., 2010). Overall, participation in mothering occupations is supported in the literature as the foundations of becoming a mother to a premature infant in the NICU.

Concepts of doing, being, belonging, and becoming align with the World Health Organization's definition of health (Wilcock & Hocking, 2015). The WHO described optimal health as the ability of an individual to engage in physical, mental, social, spiritual, and economic occupations to fulfil one's life role expectations in the absence of illness (Smith et al., 2006). Wilcock and Hocking (2015) aligned the concepts of an occupational theory of human nature to the definition of health by the WHO to include (a) physical well-being is determined by doing and becoming with the exercise of physical capabilities; (b) mental well-being is achieved by being and becoming through engagement in occupations that are productive, creative, restful, and reflective; (c) social well-being is aligned with belonging and becoming when participating in occupations with others; (d) becoming exists through doing, being, and belonging (e) doing, being, belonging, and becoming are used to support an absence of illness (pp. 15-25).

Conversely, illness or a poor sense of well-being occurs with occupational imbalance, which causes a disruption to occupation or occupational deprivation (Wilcock & Hocking, 2015). Occupational deprivation is defined as any circumstance, which prevents, removes, or withholds occupational engagement (Wilcock & Hocking, 2015). Therefore, one may imply that the limited opportunities for mothering occupations to be carried out by mothers of premature infants in a Level IV NICU may result in occupational deprivation, occupational imbalance, and feelings of a poor sense of well-being. Gibbs et al. (2016) interviewed three married couples in the NICU who showed a significant occupational disruption brought on by the premature birth of their infant. Thus, by applying the concepts of the occupational theory of human nature, the occupational therapist may gain a holistic, occupation-based view of mothering a premature infant in a Level IV NICU. From a theoretical perspective, there is a gap in the literature for mothering of high-risk infants as a construct (Miles et al., 2011), theories related to acquisition of the maternal role (Mercer, 2004), and theories for transitions to motherhood among different types of mothers (Horne et al., 2005), which should include mothers of premature infants.

Summary

The review of the literature presented information about the concept of mothering from a sociology perspective, an occupational therapy construct, and an occupational science construct. The occupation of mothering was explored as it relates to the premature infant in the NICU. Models of care were introduced as well as barriers for the implementation in the NICU. Finally, an occupational therapy and occupational science theoretical perspective was presented, and the constructs of the model and theory were applied to the concept of mothering premature infants in the NICU. Throughout the literature, gaps in knowledge were evident from understanding mothering occupations for premature infants from the mother's perspective (Fraga et al., 2019;

Gibbs et al., 2010; Gibbs et al., 2015; Gibbs et al., 2016), addressing the mother's view on family-centered developmental care (Burke, 2018; Klawetter et al., 2019; Mirlashari et al., 2019; Obeidat et al., 2009; Ramezani et al., 2014; Skene et al., 2019), addressing the barriers to presence and participation from the mother's experience of having a premature infant in a Level IV NICU (Pineda et al., 2018; Reynolds et al., 2013), mothers perceptions of care in the NICU from a variety of ethnic and cultural backgrounds (Al Maghaireh et al., 2016; Gibbs et al., 2016; Profit et al., 2017), exploring the importance of co-occupations between the mother and her premature infant (Cardin, 2020; Fraga et al., 2019), and achieving a mothering identity through mothering occupations for the premature infant in the NICU (Horne et al., 2005). In this dissertation study, a hermeneutic phenomenology approach was used to explore the lived experience of mothers of premature infants in a Level IV NICU.

Chapter 3: Methods

Introduction

This investigator explored the lived experience of mothers of premature infants in a Level IV NICU by using a qualitative, hermeneutic phenomenological approach. This chapter presents how the hermeneutic phenomenological study was conducted. The research design, research assumptions, participant selection, data collection strategies, and data analysis plan are discussed. Other considerations for the methodology and design, such as protection of human subjects, risks and benefits, trustworthiness and integrity, and strengths and limitations, are also reviewed in this chapter.

Research Design

The purpose of this hermeneutic phenomenological study was to explore the lived experience of mothers of premature infants in a Level IV NICU. For the research design, a qualitative, hermeneutic phenomenological approach was used to interview mothers of premature infants in a Level IV NICU in a large pediatric hospital located in a metropolitan city in the southeast. The main objective of using qualitative methods for research is to understand an individual's experience and their personal meaning of the experience (Creswell, 2013). More specifically, phenomenology has been described as an approach within qualitative methods that is used to explore an individual's lived experience of a particular phenomenon (Richards & Morse, 2013). Hermeneutic phenomenology is a research approach within phenomenology that is used to explore the interpretive meaning of an individual's experience within their lifeworld (Richards & Morse, 2013). Interpretive in this sense could be described as studying the concept of being in the world versus knowing the world as one seeks meaning of experiences in one's everyday live (Cohen et al., 2000). The focus of hermeneutic phenomenology is on the

interpretive meaning derived from one's experiences that are embedded in culture and shared language (Cohen et al., 2000). Hermeneutic phenomenology has been discussed as a phenomenological approach by Heidegger in the 1960s and by Van Manen in the 1990s as a way for individuals to understand how we exist in the world (Cohen et al., 2000). Furthermore, Heidegger stated that hermeneutics is the idea of *being* within the world when interpreting a phenomenon (Cohen et al., 2000). The use of interpretive meaning of another's experience of being in their own lifeworld sets hermeneutics apart from other forms of phenomenology, such as transcendental (intentionality), existential (reciprocity), and linguistical (language; Cohen et al., 2000; Richards & Morse, 2013). The term *being* comes from the German word *dasein*, which has a translation meaning of *being there* (Cohen et al., 2000). Therefore, the experiences of mothers of premature infants in a Level IV NICU was explored through the use of interviews that were analyzed using a hermeneutic phenomenological approach.

Research Assumptions

Interviewing mothers of premature infants in a Level IV NICU, using a hermeneutic phenomenological approach, the primary investigator assumed that the participants would be sharing their individual lived experiences. The primary investigator assumed that all participants would be open and honest in their responses in the interviews. The primary investigator assumed the participants would be accurate in their account of their lived experience. The primary investigator assumed the responsibility and ability to be open minded when interpreting the responses of the participants.

Setting

A large pediatric hospital in a southeast metropolitan city that has a 49-bed Level IV NICU was the setting for the dissertation study. A Level IV NICU consists of personnel and

equipment that have continuous life support, comprehensive care for extremely high-risk newborn infants, infants born weighing less than 1500 g or born less than 32 weeks' gestation, and has specialized surgical interventions (American Academy of Pediatrics, 2012). The metropolitan city in the southeast has a population of 426,821 made up of 52.3% Black or African American, 40.1% White or Caucasian, 4.6% Hispanic, 4.0% Asian, 2.3% two or more races, and 0.3% American Indian and Alaska Native (United States Census Bureau, 2018). In 2019, the Level IV NICU in the metropolitan city in the southeast admitted 512 infants. Of these infants admitted in 2019, 48% were Black or African American, 40% were White or Caucasian, 4% were Asian, and 8% were other. The payor source for the infants admitted in 2019 were 58% public insurance, 28% private insurance, 9% combined public and private, and 5% other. The Level IV NICU in the metropolitan city in the southeast admits premature infants born as early as 22 weeks' gestation. Admitting diagnoses included the following:

- Perinatal asphyxia.
- Hypoxic ischemic encephalopathy.
- Intracranial abnormalities, including Grade III or IV intraventricular hemorrhage (IVH), periventricular leukomalacia (PVL), microcephaly, meningitis, neonatal seizures, or other abnormal neurologic pathology.
- Bronchopulmonary dysplasia.
- Severe necrotizing enterocolitis or other gastrointestinal or urological abnormalities.
- History of extracorporeal membrane oxygenation (ECMO).
- Cardiopulmonary abnormalities.
- Genetic anomalies.
- Orthopedic anomalies.

- Infants with complications related to multiple gestation.

Mothers of premature infants admitted to a Level IV NICU were recruited to participate in interviews for the hermeneutic phenomenological study. Interviews were conducted in a private conference room located within the Level IV NICU.

Sampling Plan

For the hermeneutic phenomenology study, participants were mothers of premature infants in a Level IV NICU. Participants were selected using purposeful sampling. Purposeful sampling is used for the researcher to select participants based on their characteristics. Using a hermeneutic phenomenological approach, participants were recruited based on the ability to discuss experiencing place, experiencing events over time, and ways of talking about their experience (Cohen et al., 2000). Experiencing place was explored by their experience of having a premature infant admitted to the Level IV NICU. Experiencing events over time was explored through the mother's experience of being in the Level IV NICU environment for one month and longer. Ways of talking about their experience were discussed through the open-ended interview, exploring their lived experience of having a premature infant in the Level IV NICU.

Participants

Mothers of premature infants in a Level IV NICU were recruited to participate in the hermeneutic phenomenological study. Participants were recruited through the use of purposeful sampling. Participants were recruited based on inclusion and exclusion criteria.

Inclusion Criteria

Participants were mothers who identified as the primary caregiver of premature infants born less than 37 weeks' gestation admitted to in a level IV NICU. Mothers were recruited after one month of admission to the Level IV NICU. The purpose of waiting one month was to capture

mothers of premature infants who experienced a prolonged hospitalization, which was to ensure the ability to discuss events over time as indicated by hermeneutic phenomenological approach (Cohen et al., 2000). Mothers of premature infants born less than 37 weeks' gestation were recruited. The World Health Organization defines prematurity as any infant born less than 37 weeks' gestation (World Health Organization, 2018). Participants who spoke English were recruited. Participants were able to participate in interviews that lasted approximately 60 minutes to 90 minutes on two separate occasions. Participants were available to participate in the interviews, which were conducted in a private conference room located within the Level IV NICU.

Exclusion Criteria

Participants were excluded if they did not speak English. Participants were excluded if their premature infant was discharged prior to one month of hospitalization. Participants were also be excluded if they could not participate in two separate interviews that were scheduled to occur after one month of hospitalization and 2 weeks following initial interview. Participants were excluded if they could not attend a face-to-face interview.

Sample Size

The dissertation study used a hermeneutic phenomenological approach; therefore, the sample size was between eight to 10 participants. Creswell (2013) stated an appropriate sample size for phenomenology studies are six to 10 participants. Given the dependency of recruitment based on length of hospitalization and the impact of COVID-19, eight participants were the targeted sample size. Participants were recruited until the enrollment number was fulfilled.

Protection of Human Subjects

The primary investigator obtained institutional review board (IRB) approval from Nova Southeastern University and from the pediatric hospital. Informed consent was obtained by the primary investigator. The primary investigator completed human subjects research training and was able to explain the dissertation study and answer questions. The primary investigator reviewed the informed consent with each participant. Participants were given the informed consent with a chance to review and ask any questions prior to signing. A copy of the signed informed consent was provided to the participants. For participants less than 18 years of age, informed consent was obtained from a parent/legal guardian. All data obtained during the dissertation study was confidential. Protected health information (PHI) was protected by assigning participants with an identification number that was stored on a password-protected server. Participants were assigned a pseudonym to ensure confidentiality. Participants were allowed to withdraw at any given time.

Risks and Benefits of Participation

There was minimal risk associated with participation in this dissertation study. Some participants may have felt uncomfortable discussing their lived experience during the interviews. The participants did not have to answer or explain anything they did not wish to during the interviews. There was a small risk of someone outside of the dissertation study seeing some of the identifying information of the participants; however, there was a data protection plan in place. All data was stored on a password-protected computer. Participants were also given pseudonyms for confidentiality and protection of identity.

The benefits of participating in this dissertation study were to provide in-depth information of the lived experience of having a premature infant admitted to a Level IV NICU.

The information obtained during the interviews may have highlighted the mother's strengths and resilience during the hospitalization of their premature infant in the Level IV NICU. Information obtained during the interviews may have also led to improvements of family-centered developmental care, family supports, hospital resources, and hospital policies. This dissertation study may or may not have directly benefitted the participants.

Data Storage

Data collection included obtaining demographic information, audio recordings, and field notes. Demographic information included the mother's age, ethnicity, education level, current employment status, number of children, infant's diagnosis, infant's gestational age, and infant's length of hospitalization. Before beginning the interview, participants were informed that their identity would remain confidential by using pseudonyms rather than participant's names on study records for confidentiality. Until data analysis was complete, audiotapes and other information was stored in a locked cabinet and password- and firewall-protected computer. The code sheet to identify the participant was stored separately from the data to ensure protection of privacy. Data was stored on secure servers. Only the primary investigator was allowed access to the audio tapes, code sheets, and participant information. Audiotapes and transcripts will be kept for the appropriate amount of time based on IRB designation and recommendation, a minimum of 3 years. The primary investigator's dissertation committee had access to transcripts and data analysis upon their discretion. Identifiers were removed from all records during transcription. Before dissemination of findings, all information that might have revealed the identity of a participant were eliminated.

Procedures

Participants were recruited to participate in the dissertation study based on infant's gestational age, admission to the Level IV NICU, and current length of stay. The timeline for the dissertation study for recruitment and interviews was 10 weeks to 12 weeks. Following IRB approval, participants were recruited by the current occupational therapy caseload of the primary investigator in the Level IV NICU or other rehabilitation staff's caseload in the Level IV NICU. Once identified, the participants were contacted either in person in the Level IV NICU or via telephone call. The primary investigator obtained a written informed consent from all participants. Pseudonyms were used to protect participants' identities. Participants were allowed to withdraw at any given time. Prior to the obtaining informed consent and conducting interviews, the primary investigator performed critical reflection in order to reduce any bias in the form of bracketing. The process of identifying any prejudices or bias the investigator may have during the dissertation study has been referred to as bracketing in hermeneutic phenomenology (Cohen et al., 2000). Bracketing is an important process during data collection and data analysis as the researcher is allowed to reflect on ideas and postulations about the phenomenon being explored (Stanley & Nayar, 2014). Once informed consent was obtained, participants were asked to participate in two individual, semi-structured interviews that used an introductory, open-ended inquiry, "Tell me about your pregnancy and delivery experience" (see Appendix A) and with the use of probing questions. Interviews took place at a time convenient to the participant. The interviews were recorded via a handheld voice recorder. The initial interview occurred following one month of continuous admission to the Level IV NICU. Examples of probing questions included "What were your initial thoughts when you learned your baby would be admitted to a NICU," "Can you tell me about your experience with caring for your premature

infant while in the NICU," "How has having a premature infant different from previous caregiving experiences?", and "Tell me about how the NICU environment and staff helped you care for your baby." During the interview, the investigator took field notes based on observations, body language, and nonverbal communication.

Second generation qualitative studies should use more linguistic approaches to gathering qualitative data (Frank & Polkinghorne, 2010). Therefore, the participants were asked to participate in a second interview 2 weeks following the initial interview to gather more in-depth data and allow time for the participants to reflect on their lived experience. During the follow-up second interview, the open-ended question that started the interview was, "Is there anything you would like to further discuss regarding your experience of having a premature infant in the NICU now that you have had some time to think since your first interview?" (see Appendix B). During the follow-up interview, the primary investigator took field notes to document any observations, body language, and nonverbal communication. At the conclusion of the interviews, the audiotapes were transcribed, and field notes were transcribed. To ensure trustworthiness and integrity, the primary investigator conducted member checking by giving the participants a transcript of their interviews for any edits or corrections. The participants had 2 weeks to complete any edits or corrections as well as checking authenticity of the generated themes. The primary investigator presented the findings to the participants at the conclusion of the dissertation study.

Data Collection Instruments

The investigator explored the lived experience of mothers of premature infants in a Level IV NICU by using a qualitative, hermeneutic phenomenological approach. Interviews with open-ended questions that lasted 60 minutes to 90 minutes were used for data collection. The

interviews were recorded using a digital voice recorder. Interviews were conducted at one month of admission, and 2 weeks following initial interview. In addition to the digital audio file, demographic data were collected from each participant prior to the initial interview and entered into an Excel file. Field notes were also used during the data collection process.

Demographic Data

Demographic information included the mother's age, ethnicity, education level, current employment status, number of children, infant's diagnosis, infant's gestational age, and infant's length of hospitalization. Demographic data were collected before each initial interview. The data were documented in an Excel file. The Excel file was stored in a locked cabinet on a password- and firewall-protected computer.

Interview Questions

The initial interview occurred following one month of admission to the Level IV NICU. The introductory, open-ended inquiry was, "Tell me about your pregnancy and delivery experience." Probing questions were utilized based on the participant's responses to gain more in-depth knowledge and information regarding the mother's lived experience of having a premature infant admitted to a Level IV NICU (see Appendix A). Examples of probing questions included "What were your initial thoughts when you learned your baby would be admitted to a NICU," "Can you tell me about your experience with caring for your premature infant while in the NICU," "How has having a premature infant differed from previous caregiving experiences?", and "How has the NICU environment and staff helped you care for your baby?" During the second interview, the open-ended question that began the interview was, "Is there anything you would like to further discuss regarding your experience of having a premature

infant in the NICU now that you have had some time to think since your first interview?" (See Appendix B).

Field Notes

Field notes were taken during each of the interviews. Field notes in hermeneutic phenomenology studies are useful in capturing details that are not capable of being noted from audiotape transcriptions (Cohen et al., 2000). Field notes are also important for obtaining data that becomes apparent when the voice recorder is turned off or has not started recording (Cohen et al., 2000). The primary investigator took field notes during each interview with every participant to gather observational data. Per Cohen et al. (2000), field notes are used for the researcher to perform self-evaluations. Therefore, the primary investigator also used field notes to document any reflections regarding the responses to the participants during the interviews. Another reason field notes are useful during interviews are to notate any ideas or insights into the participant's experiences (Cohen et al., 2000). Field notes were written in a timely manner during and following each interview. The field notes were also transcribed in a Word document to allow for data analysis through coding techniques.

Data Management and Organization

The data management plan and organization included transcriptions of the digital audio file and field notes from each interview. A digital copy of each interview as well as the field notes were kept protected in a secure location. Transcripts from the interviews and the field notes were coded. Codes were organized for identification of themes.

Transcription

For analysis of the data, the primary investigator transcribed the interviews from the digital audio file verbatim. By transcribing the digital audio file verbatim, the primary

investigator documented each interview word for word in a Word document. Field notes were also transferred from the notepad used during the interviews into a Word document. Each line of the word document was numbered. Margins of the Word document were widened to 2 inches on each side to allow for note taking and writing codes.

Demographic Data Analysis

The demographic data obtained from each participant prior to the initial interview were entered into an Excel file. The demographic data were analyzed using descriptive statistics. Descriptive statistics were used to summarize characteristics of each participant. Descriptive statistics focus on describing, summarizing, or explaining a set of data (Tashakkori & Teddlie, 2010).

Data Analysis

The main objective of data analysis using a hermeneutic phenomenological approach is to correctly report and describe the meaning for the individual's lived experience (Cohen et al., 2000). In order to do so, the primary investigator began by immersing herself in the data by reading and rereading all of the transcripts. Cohen et al. (2000) discussed how immersing oneself in the data allows for a greater understanding of the data when codes may begin to appear. The next step of data analysis began by performing data reduction. Data reduction is used to remove irrelevant data that is similar to the process of editing texts (Cohen et al., 2000). Following the data reduction, coding of the data began.

Coding data included the process of immersion into the data of the transcripts and the field notes. By thoroughly reading through the transcripts and fieldnotes, the primary investigator was able to achieve an overall general sense of the data before formal coding began. In hermeneutic phenomenology, the process of familiarizing oneself with the data before actual

coding commences is called the hermeneutic circle (Cohen et al., 2000). Each transcript and accompanying fieldnotes were coded in the same manner by reading and rereading the data following initial coding. This process improves familiarity of the data. Comparing the data from each transcript to the fieldnotes also improved understanding the data from the participant's perspective. Different colored highlighters and colored pencils were used for coding the data to indicate similar statements and ideas. There was an index of each color for identification purposes. Once color coded, similar colors were grouped together to begin forming categories by having the data cut out and placed into piles according to each color. These categories included similar statements and ideas from the data. Each color-coded set of data was placed on a tabletop to allow the primary investigator to form, arrange, and rearrange the data into categories. The categories and codes were then placed together to identify themes. Thematic analysis occurs when the data are highlighted, and prospective themes are notated in the margins of the document (Cohen et al., 2000). Thematic analysis was used for analyzing patterns from the data and exploring participants responses. All similar notations were identified by being color-coded, grouped together by categories, and analyzed for the development of overall themes. Exemplar quotes were used in the narrative report to emphasize each of the themes.

Trustworthiness and Integrity

Authors of qualitative studies achieve trustworthiness and integrity by demonstrating transferability, credibility, and dependability during the research process (Hussein et al., 2015). Transferability is often achieved by indicating the finding may have meaning to individuals in similar situations or contexts (Hussein et al., 2015). Likewise, by emphasizing the individual's lived experience through rich text (Frank & Polkinghorne, 2010), the primary investigator achieved transferability. Therefore, the primary investigator provided a full description of the

dissertation study environment and a thick description of the lived experience of mothers of premature infants in a Level IV NICU to increase the likelihood of transferability of the dissertation study.

Credibility involves describing the phenomenon of study in an intense manner so that others who have been in similar situations will recognize it (Hussein et al., 2015). To achieve credibility, researchers must immerse themselves in the data, assess all data, and perform member checking of the data (Hussein et al., 2015). The researchers must immerse themselves in the data to have a complete picture of the data (Cohen et al., 2000). Assessing all data involves looking upon not only the transcripts of the interviews but also the field notes (Cohen et al., 2000). Member checking involves participants reviewing their transcripts and provide any edits to the data (Creswell, 2013). The primary investigator immersed herself into the data, assessed all data, conducted member checking, and ensured transparency throughout the process to ensure credibility of the dissertation study.

Dependability relates to the trustworthiness of the study and the researcher's ability to provide reliable data (Hussein et al., 2015). Dependability relies on management of bias, triangulation of data, and reflexivity (Lysack et al., 2017). In hermeneutic phenomenological studies, triangulation is not the focus during data collection or data analysis (Cohen et al., 2000). Reflexivity is a process of self-examination and is an important aspect of trustworthiness during a qualitative study (Lysack et al., 2017), which was also achieved through the process of bracketing to identify and acknowledge any bias the primary investigator had as an occupational therapist in the Level IV NICU. The primary investigator performed reflective journaling of any preconceptions, assumptions, or criticisms experienced during the dissertation study. Of note, data saturation is a term typically used in grounded theory studies when the researcher seeks to

gather enough data to fully understand the experience being studied (Cohen et al., 2000). In hermeneutic phenomenology, the researcher appreciates that each individual's experience is unique, how they make meaning of their individualized experience, and how they interpret their personalized lived experience (Cohen et al., 2000). Hence, in this dissertation study, data saturation was not the intent as the primary investigator gathered data from each participant to explore the lived experience of mothers of premature infant in a Level IV NICU.

Strengths and Limitations of the Research Design

A strength of this dissertation study was that the data were obtained in the Level IV NICU where the participants were currently experiencing having a premature infant admitted in the hospital. The primary investigator is a member of the neonatal rehabilitation staff in the Level IV NICU, which was a strength of the design due to the nature of therapeutic relationships. The data collection method was used for rich data to be obtained. Another strength to the research design was the follow-up interview 2 weeks after the initial interview, which had more in-depth narrative and insight. Using open-ended questions and probing, the primary investigator obtained a greater understanding of the lived experience of each mother. A limitation to the dissertation study was a small sample size. However, using a hermeneutic phenomenological approach was used for an adequate sample size to match the setting and clinical experience of the investigator (Cohen et al., 2000). In this dissertation study, length of hospitalization directly influenced the sample size. Furthermore, the participants were recruited from one Level IV NICU in a pediatric hospital in a metropolitan city in the south.

Summary

The primary investigator used a hermeneutic, phenomenological approach to the research design. This chapter reviewed the research methodology used by the primary investigator to

explore the lived experience of mothers of premature infants in a Level IV NICU. The procedures were explained as well as the data analysis plan. The strengths and limitations of the dissertation study were discussed. In conclusion, the methodology of the dissertation study has been thoroughly explained in this chapter.

Chapter 4: Findings

Introduction

The purpose of this chapter is to present the findings of the thematic analysis of in-depth, semi-structured interviews, exploring the lived experience of eight mothers of premature infants in a Level IV NICU. There were two separate, individual semi-structured interviews between the investigator and the participants, which occurred 2 weeks apart and lasted approximately 60 minutes. The semi-structured interviews were guided by open-ended questions that allowed for probing questions to occur to gain more insight into the lived experience of mothers of premature infants in a Level IV NICU. The data were analyzed using a hermeneutic phenomenological approach to correctly report and describe the meaning behind the individual's lived experience (Cohen et al., 2000). In first part of the findings in this chapter, the investigator discusses the investigator's experience with data collection and bracketing. The process of identifying any prejudices or bias the investigator may have during the study has been referred to as bracketing in hermeneutic phenomenology (Cohen et al., 2000). Demographics of each participant were also obtained prior to the initial interview. The demographics of each participant is discussed in the second part of the findings in this chapter. The third part of the findings are an overview of the themes and subthemes. The fourth part of the chapter includes in-depth descriptions of the themes and subthemes of the lived experience of mothers of premature infants in a Level IV NICU.

Data Analysis Findings

Primary Investigator's Experience of Data Collection and Bracketing

Prior to the obtaining informed consent, demographics, and conducting interviews, the primary investigator performed critical reflection in order to reduce any bias in the form of

bracketing. Bracketing is an important process during data collection and data analysis as the investigator is allowed to reflect on ideas and postulations about the phenomenon being explored (Stanley & Nayar, 2014). The primary investigator used a journal prior to and at the conclusion of each interview to reflect on any preconceived notions toward the information obtained during the mothers' accounts of their lived experience of having a premature infant in the NICU.

The journal was an important process as the primary investigator due to the clinical position as an occupational therapist in the Level IV NICU for the past 7 years. The primary investigator documented reflections and reactions during the interviews so that the primary investigator maintained an open mind during each individual interview with the participants. There were three themes that emerged from the journal: (a) navigating the investigator role in the clinical setting, (b) emotional feelings, and (c) influence of COVID-19 as a worldwide pandemic on the qualitative research process.

The first theme of navigating the primary investigator role in the clinical setting occurred as a result of serving two roles in the NICU: one of occupational therapist and the other as the primary investigator. One of the participants was on the primary investigator's occupational therapy caseload, which posed a challenge as the primary investigator. Due to access of medical charts, the primary investigator had to notate any bias that may have occurred during the interviews and separate clinical knowledge from the information sought from the participants. The primary investigator often felt compelled to cross boundaries at times during the interviews; however, being able to process these feelings in the journal was used for the primary investigator to maintain a more neutral ground. One excerpt from the journal highlights this obstacle:

> This interview was a bit challenging for me as the participant's baby was on my current caseload. Already knowing many facts about the reasons for being in the NICU from doing chart reviews and having already evaluated the baby a month before the interview made the interview a little easier. However, I did struggle with avoiding leading

> questions and knowing when to allow the participant to elaborate. I sensed a hesitation with some of her responses to the questions. Maybe it was out of embarrassment [because] we have an established therapist and patient relationship? I am finding it hard to maintain a neutral interviewer and not the OT during this interview.

To mediate the concern of being a neutral interviewer, the primary investigator took notes about topics the participant was discussing to later address during the OT sessions with her baby. The primary investigator found it was important to go back to avoid making this a direct topic during the interview. Furthermore, the primary investigator needed to focus more on the research questions versus the OT treatments that were being used for her baby's plan of care. In another journal entry, the primary investigator documented how difficult it was interviewing a mother who was not on the primary investigator's caseload. The primary investigator found it challenging to avoid asking questions in regard to the participant's experience working with another therapist. This excerpt indicates this hesitation:

> The first participant was new to me as her baby was on another OT's caseload. I fought the urge to ask questions related to her encounters with the treating OT and to give my own opinions of treatment interventions. I think this was the hardest part outside of avoiding leading questions and inquiry.

Another excerpt from the journal following an interview with a young mother also reflects on the struggle of maintaining an investigator role when listening to her account of being a mother to a premature infant:

> Maintaining two different roles, investigator and OT, are difficult as I find myself wanting to give advice and opinions. I want to give advice to her about how to smooth things over with the nursing staff but feel like this would be inappropriate. I wonder if this study would have been easier if I was not a primary OT in this unit?

The second theme that surfaced during the interviews was emotional feelings. Many of the stories the mothers were telling of their lived experience of having a premature infant who was then admitted to a Level IV NICU brought out feelings of sadness. The mothers often displayed raw emotions, and the primary investigator felt empathy toward the mothers. The

primary investigator felt pressure to maintain composure during the interviews. This pressure was evident by the following excerpt:

> I feel very sad and sorry for this mom. She has gone through a lot and has limited support. She seems very isolated and lonely. I wonder if [it] will always be the case as an investigator, [and] I am having a hard time keeping the therapist in me on the back burner and wanting to comfort her. I need to see about any resources to help me prepare a little better for these feelings and needing to maintain my own composure during the interviews. She spoke about her sister who recently died unexpectedly, and I wanted to give her a hug. I also felt torn about giving her advice as a therapist and overstepping my boundaries as an investigator. I think this [duality] has been one of the hardest things to do during this study.

An unexpected event that occurred during the data collection process that greatly affected the primary investigator was the death of a participant's premature infant. The primary investigator had not prepared mentally or emotionally for the possibility of a death happening during the dissertation study. The primary investigator reflected upon this death in the journal by the following excerpt:

> The first participant never got to participate in the follow-up interview as her baby passed away following cardiac surgery and another bout of NEC [necrotizing enterocolitis]. She was very distraught as he suddenly deteriorated, and she had to cancel the follow-up interview. I had not considered this to be a possibility and caused me to pause data collection for a couple of weeks. Although our relationship only consisted of the hour spent together during the first interview, I felt somehow invested in her and her baby. I allowed her to cry and grieve while I attempted to hold in my own emotions. I was not sure how to comfort her while maintaining professionalism. And with COVID-19, I felt like hugging was inappropriate. I cried on my way home from work that day, and I really thought about the vulnerability and fragility of not only the mothers but the babies in the NICU.

The third theme that emerged from the journal was the influence of COVID-19 as a worldwide pandemic on the qualitative research process. There were new hospital policies due to COVID-19 affecting visitation rules, which obstructed the ability to consent participants. The primary investigator had not anticipated this obstacle when designing the dissertation study. The primary investigator noted the difficulties of not being able to decipher nonverbal language

during the interviews because of the use of masks and face shields per the hospital policies related to COVID-19. The following excerpts indicate these occurrences:

> Another barrier to consenting participants was the hospital policy changing visitation rules due to COVD-19. Hospital policy also required face coverings and eye protection for all staff and face coverings for all visitors. Mandatory masking and face shields were policy in the hospital due to COVID-19. I found it difficult to read nonverbal communication as half of her face was covered. I noticed that I was paying closer attention to fidgety movements in the chair instead of facial expressions due to the inability to see her lower face and mouth. I think the inability to read nonverbal language and facial expressions will be a barrier during the data collection and analysis process.

Another issue with COVID-19 was the impact the visitation policy had on the mothers, which was evident in the description of this situation with one of the mothers in particular. The following excerpt highlights this situation.

> Mom was tearful today when talking about return to work in the school system. Not only is she torn about not being able to visit as often but also of the uncertainty of the effect of COVID-19 on her health if students are returning to the classroom. Her story has pulled on my heart strings as I feel she is so isolated, and COVID-19 has made it worse due to the visitation policy.

The primary investigator described how qualitative research uses non-verbal language during interviews as part of the data collection process. COVID-19 placed an unforeseen barrier to the ability to read non-verbal language due to the mandatory face coverings and eye coverings per the hospital's policy. The following excerpt emphasizes how the primary investigator struggled with this barrier.

> Finishing up the last interview, I [cannot] help but to reflect on how a worldwide pandemic has influenced not only medical care in a hospital environment but also my ability as an investigator to conduct interviews where body language plays a role in data collection. Not only did I feel non-connected to the participants due to the face and eye coverings, but also from the distance between us during the interview. I could not shake hands or place a comforting hand on someone's shoulder when they were tearful and upset. But maybe this would have been inappropriate anyway as I assumed the investigator role and relinquished my OT role. I also felt a time restraint during the interviews. The participants appeared uncomfortable at times being in the small conference room and I wonder if this influenced the amount of information they divulged.

In summary, reflexivity is a process of self-examination and is an important aspect of trustworthiness during a qualitative study (Lysack et al., 2017), which was achieved through the process of bracketing to identify and acknowledge any bias the primary investigator had as an occupational therapist in the Level IV NICU. The primary investigator performed reflective journaling of any preconceptions, assumptions, or criticisms that may have occurred during the dissertation study. The process of journaling prior to and during the interviews gave an outlet to reflect any biases the primary investigator may have had toward mothers of premature infants. The primary investigator was afforded an opportunity to perform critical reflection of her experience of being an investigator in the clinical environment where she also is employed as an occupational therapist.

Demographics of the Participants and Their Premature Infants

In this hermeneutic, phenomenological study, there were eight participants. All eight of the participants were mothers of premature infants admitted to a Level IV NICU who had been admitted at least 1 month. Of the participants, six were Black and two were White-Caucasian. The participants' ages ranged from 19 years to 39 years old. The participants lived between 20 miles to 65 miles away from the hospital. The participants' education levels consisted of one general education development (GED), one attended some college courses, three associate degrees, and three bachelor's degrees. The participants' employment status consisted of one stay-at-home mom, one unemployed, one current student, one part-time, and four full-time. The following table presents demographic information for each of the participants (see Table 1).

Table 1

Demographics of Participants

Participant	Age	Race	Education level	Employment status	Number of children	Distance from hospital
Marsha	39	Black	Associate	Part-time	6	28 miles
Emily	36	White	Some college	Stay-at-home mom	4	65 miles
Rebecca	19	White	GED	Unemployed	1	46 miles
Erica	35	Black	Bachelor's	Fulltime	1	30 miles
Crystal	28	Black	Associate	Current student	2	25 miles
Amy	27	Black	Bachelor's	Fulltime	1	28 miles
Michelle	31	Black	Bachelor's	Fulltime	1	30 miles
Kristina	33	Black	Associate	Fulltime	1	62 miles

Note: Names of participants were changed to protect anonymity.

The demographics of the participants' premature infants consisted of the type of therapy services the infants were receiving: (a) occupational therapy, (a) physical therapy, and (c) speech therapy or a combination of any of the three disciplines. Many of the premature infants received either one type of therapy service or a combination of the three. Of the therapy services provided, three premature infants received only OT, one premature infant received only PT, 1 premature infant received OT and ST, 1 premature infant received PT and ST, and 2 premature infants received OT, PT, and ST. The premature infants' gestational ages ranged from 23 to 35 weeks. Prematurity was not the sole reason for being admitted to the level IV NICU as all of the premature infants had other co-morbidities which required surgical interventions. The hospital length of stay at the time of the initial interviews ranged from 1 month and 2 weeks up to 4 months. The following table provides demographic information for each of the participants' premature infant (See Table 2).

Table 2

Demographics of Participants' Premature Infants

Participant	Therapy services	Infant's gestational age	Infant's diagnosis	Length of stay
Marsha	OT	31 weeks	Trisomy 21, duodenal atresia, VSD, IVH grade 1, ROP, BPD, NEC	1 month, 14 days
Emily	OT	35 weeks	Trisomy 18, TEF/EA, VSD, PDA, hemorrhage of left occipital lobe, heart block 2nd degree	1 month, 19 days
Rebecca	PT, ST	30 weeks	NEC, anemia, intestinal bacterial overgrowth	2 months
Erica	OT, PT, ST	32 weeks	BPD, IVH grade 1, pulmonary hypertension, hemiparesis of right diaphragm	4 months
Crystal	OT, ST	23 weeks 4 days	SIP, ROP, fungal sepsis, apnea	2 months
Amy	OT	25 weeks	Meconium plug syndrome, small bowel perforation, BPD, ROP	2 months
Michelle	PT	26 weeks 2 days	PDA, multiple organ failure, BPD	1 month, 14 days
Kristina	OT, PT, ST	25 weeks 1 day	NEC, PDA, IVH grade 2, BPD, ROP	2 months, 27 days

Note: Names of participants were changed to protect anonymity.

Individual Description of the Lived Experience

In this section, each participant's background of becoming a mother to a premature infant who had been admitted to a Level IV NICU is explored. Each participant's experience of being pregnant and of their delivery experience of their premature infant is described in detail. Each participant's name was changed to protect anonymity. In addition, some of the transcripts may have been altered to protect identification of participants. Three asterisks will be used to indicate any changes or omissions in the excerpts to protect anonymity. The research questions included "What is the lived experience of mothers of premature infants in a Level IV NICU?" and "What is the mothers' experience of performing mothering occupations in the Level IV NICU?"

Participant #1 Marsha. Marsha is a 39-year-old Black mother who found out she was pregnant at 7 weeks' gestation. She is a mother to five other children, and the oldest is 20 years old and the youngest is 7 years old. She is originally from a Caribbean Island and has been living in the Southeastern United States for more than 15 years. She reported that the children were born in her home country but also in the United States. She has an associate degree and works part time as a supervisor. During the interview, Marsha provided great detail of her pregnancy and delivery experience as well as her experience of performing mothering occupations in the NICU (I = investigator, M = Marsha).

I: Tell me about your pregnancy and delivery experience.

M: Pregnancy as in from the beginning?

I: Yes.

M: When I found out I was about seven-weeks pregnant and started feeling sick, nauseous and vomiting. Went to the doctor and found out that I was pregnant. I was already 38 years old. I'm thinking 38! My last one is 7 years old. I already have five. What did I do?

I: Yes.

> M: But for all my pregnancies, I've always been really sick, anemic. It gets worse when I'm pregnant.

Marsha discussed in detail how she felt sick throughout the pregnancy. She also stated she never missed any of her prenatal appointments. She was able to take the Harmony test in which she was mostly interested in finding out the sex of the baby. It never crossed her mind that anything could be of concern with the baby. Here is discussed in the following excerpt.

> M: I took the Harmony test. I was more into finding out what the sex of the baby was at that time. I got a phone call finally when that test came back. They sat with me to talk to me. It told me this is a percentage chance of having a baby with T21. I never heard about T21 until this pregnancy. I didn't know what it was. I started to Google it. They told me it's more something like Down syndrome. They gave me an appointment to see a specialist.

Marsha voiced her frustration with seeing a different doctor at every appointment. She stated that it was because of her insurance that she saw a different doctor at every visit, which is highlighted in the following excerpt.

> M: I saw a different doctor all the time. I've never been to that before any pregnancy. I've always seen the same doctor. So, I took the tests. I found out what was going on. I went to my first visit where they did the ultrasound. Everything looked good, measurements. Everything was fine. Measured the arms. You were looking for the fluid behind the neck. There was none. They did mention the absent nose bridge. But it was too early in my pregnancy. Again, I will see a different doctor all the time. I went there for my doctor's visits, which I didn't like. So that is how *** my insurance does it, I guess.
>
> I: So, oh, and this is like a new insurance that you didn't have for the last pregnancies?
>
> M: Yeah. I mean, my other kids were born here in the *** United States. But I also had kids back home in the *** Caribbean. But this was the first time with this *** insurance. So, it was kind of different to me. I didn't know this is how I was going to be. And I thought it was OK. But for me, it just kind of sounded kind of strange or odd. I don't know.

Another question that Marsha was asked during one of her appointments was whether or not she wanted to terminate the pregnancy.

> M: Do you want to continue? I said, why not? They also told me about this test where they inject a needle into your stomach to get that fluid.

I: Amniocentesis.

M: Yeah, I denied it. Because they do. They did mention it. They create an early abruption. And you can also lose a baby.

She decided to keep going with the pregnancy. Her main source of frustration was having to see a different doctor at every visit. In the next excerpt, when asked about her delivery experience, she was able to detail how she unexpectedly was admitted to the hospital following an ultrasound appointment.

M: We did the ultrasound. We're just going to go ahead and admit you like admit me. Now, I wasn't expecting to go to the hospital, and they were going to keep me. I didn't take anything. So, she came back. They were waiting for, I guess for whomever reads the ultrasound, whoever does that. They were waiting for that to come back when it did, they were like we are going to admit you. I'm asking, what do you mean like? I mean, what's going on? Oh, your baby's not measuring what he's supposed to be. And right now, it looks like your baby is only about a pound and a half like, well, that's impossible because I've been to the doctor all the time. They're listening. They're measuring and everything seems fine. Not realizing all this extra fluid.

I: Like false measurements?

M: Yes.

Marsha delivered her baby boy at 31 weeks' gestation via cesarean section. Not only was he premature, but he also had Trisomy 21 (T21), duodenal atresia, and ventricular septal defect (VSD). He was directly admitted to the birth hospital's NICU following delivery. During his admission to the NICU, he developed intraventricular hemorrhage Grade 1, retinopathy of prematurity (ROP), bronchopulmonary dysplasia (BPD), and necrotizing enterocolitis (NEC). In the following excerpt, Marsha discussed how he was required to gain weight at the birth hospital before he was transferred to the Level IV NICU for surgical intervention for duodenal atresia and VSD.

M: We're going to transfer your baby, 'cause they did say they were trying to get him on a particular weight before they sent him here because we stayed there about a week. All a

> bit more over a week. I know when I was discharged and I came in like probably 2 days after, she's like, I'm not going to keep your baby here because I really need him to grow.
>
> I: It's so different from your other kids.
>
> M: All different.

Once her baby was born, Marsha described the experience of seeing her baby for the first time. She became tearful when speaking about this experience, which is evident in the following excerpt.

> I: What were your initial thoughts when you learned that he would be admitted to the NICU, and then transferred to this NICU because now you've had a week at *** the birth hospital and then transferred here? What kind of feelings were you having?
>
> M: Oh, from the time I saw him, because of how small he was, I was afraid because again, I've never been in this situation before, having a baby, he's not able to eat. He had to grow. He was so tiny. I mean, you could literally see the bones in his body. And, I've never been here before. It's kind of scary.

Marsha was also able to describe a typical day for her and her baby in the NICU. Although she lives 28 miles away from the hospital, it took her an hour to get from her house to the NICU. This perceived barrier to visitation did not seem to interfere with her bedside presence as she stated she visits daily. She was also able to describe the mothering occupations she was able to do when she was at the baby's bedside. In the next excerpt, Marsha discussed a typical day for her in the NICU.

> I: So now you guys have been here for a good six weeks. So, tell me about a typical day for you and your baby here in the NICU.
>
> M: At 5:30 my alarm goes off and I get up. Wake my kids up. Get them ready to go to school. And I was out the door, out the door right behind them. I'll make my way here. But at first, I couldn't drive. So, I had to wait around. Can someone bring me here? Because I'm still new to *** this area. I'll make my way. I'll sit around till about 12:00, 12:30, and I'll head back because it's an hour drive for me. This is an hour to and from. And I was doing this every day. I try to be here most times when they do with their rounds. And I can sit, and I can hear. This is what we're doing today. This is what happened overnight. Also, I've never seen a diaper that small, you know?

> I: And speaking of diapers, this is a good segue. How do you feel like you're doing those caregiving tasks for him while you're here at the bedside?
>
> M: They are like clockwork every day. Yeah, every 4 hours. And they've always said, would you like to change his diaper? Oh, my. I could do that?! Would you like to do this? Oh, my, oh okay. Sure! Why not?
>
> I: Are there any other typical caregiving activities that you feel like you're doing or are missing out on?
>
> M: Holding more often most definitely. Most of what happened is I'll come here all day. I can sit on all the time. Time is just going and then I have to go. And that's like the hardest part because who has a baby and has to leave the baby behind? So, it's been kind of difficult. But at the same time, my mind has been at ease because I've been told, I've seen for myself, your baby is in a good place. So not one time I've been uncomfortable or worried like what was gonna happen. I mean, I have my days when I'm like, you don't want to get a phone call. But like I said, everything moving forward from since he's been here has been positive, has been good. So, it's a little bit more at ease while at the same time you come here, you spend time with your baby and then have to walk away, which is kind of difficult. I know a lot of times I come in and they'll ask me, would you like to hold him today? He's kind of small and all these wires. So, it's a lot to take him from the bed and holding and you want to hold him. But at the same time, I still want to be very careful. I'm like all this beeping like it's kind of scary because I don't know what it is. They did tell me this is a heart rate. This is pressure. This is his blood pressure. This is what the oxygen is doing. This is what's going on here. OK. It's kind of scary still because the light is still blinking and I say, what's going on? So, I mean, like today when you came, I was holding because now a lot of the tubes and lines are gone, which is good.

Marsha was able to talk about the mothering occupations she was able to engage in at bedside with her baby with the support of nursing staff, such as changing diapers and holding him. She also described feelings of hesitation and fearfulness of harming her baby because he was so tiny and fragile. There were still mothering occupations that she had not been able to complete like bathing and breastfeeding due to his medical needs.

To conclude, Marsha was unable to participate in the follow-up interview due to the unexpected death of her baby during the week after the initial interview. Her account of her lived experience of being pregnant, delivering a premature infant, and being admitted to a Level IV NICU was thoroughly detailed. She was able to enthusiastically share her experience of

mothering in a level IV NICU. She was able to articulate how different this pregnancy and delivery experience was compared with her other pregnancies. This difference was evident when she was discussing how fearful it felt performing mothering occupations in the NICU because of the medical equipment and the fragility of her baby, which was different from her experience with her other children.

Participant #2 Emily. Emily is a 36-year-old White mother who found out her baby was going to be born with multiple medical needs at 12 weeks post menstrual age. She went into preterm labor at 31 weeks' gestation. She is a mother to three other children whose ages ranged from 12 years old to 5 years old. She and her husband had been trying to conceive for the past 3 years with two miscarriages prior to becoming pregnant this last time. Emily is a stay-at-home mom who had taken some college courses after high school. Emily appeared to be shy, soft spoken, and quiet at times during the interviews. Despite this demeanor, she was able to talk about her experience during her pregnancy, delivery of her baby, and mothering in the Level IV NICU (I = investigator, E = Emily).

> I: Tell me about your pregnancy and delivery experience.
>
> E: So, we took the progenity test and the first one failed. They said that there was something wrong. That there is either not enough for a sample, or it just didn't mix right when they went to test it. So, the second test showed that she had 39% chance of trisomy 18. And then, I had to start seeing a specialist. They found findings, and the biggest one was the heart defect. So, we knew that she was going to have a heart defect. When she was born, our labor and delivery nurse just stepped out the door. So, my husband, it was like 1:00 in the morning, and I told my husband that something's going on. I'm contracting. Go get the nurse. And she was born without any medical help. At 2 days *** of life, they realized they couldn't do a feeding tube. And that's when I found out about the TEF/EA and they started talking comfort care.
>
> I: Was she in the NICU at the birth hospital?
>
> E: Yes.

> I: And so, what were your initial thoughts when you learned that she was going to be right after birth admitted to the NICU?
>
> E: Well, I knew before birth, they told me according to how her breathing was, is that we, she would either go immediately or we might get a little bit of time with her. We got maybe 2 or 3 minutes with her before they swept her away *** to the NICU.

Emily appeared to have been well informed about her baby's prenatal diagnosis up until the medical staff was unable to pass a nasogastric (NG) tube for feeding her and it was discovered her baby had tracheoesophageal fistula/esophageal atresia (TEF/EA). At that time, the medical staff began talking about comfort care and the need for surgery to place a gastronomy tube for nutrition. Emily's baby was going to need surgery to repair her TEF/EA and place a gastronomy tube for her to gain enough weight prior to undergoing cardiac surgery for repair of her ventricular septal defect. Emily's baby was also diagnosed in the NICU with a patent ductus arteriosus (PDA), hemorrhage of left occipital lobe, and heart block in the 2nd degree. Although Emily was informed of the medical needs and complexity of her baby, she was still in awe of her first NICU experience. This experience was discussed in the following excerpt.

> I: Were you introduced to the NICU while you were still pregnant like a tour or anything?
>
> E: No. I had delivered three other kids at the hospital. I never been in the NICU. But I had the day that I went into labor, I had an appointment, and I was gonna go walk over to the hospital then. So, I didn't quite make it to that next appointment for the tour. So, yes, it was eye opening experience first walking into a NICU and then it's such a different experience being here and coming into this NICU.
>
> I: Compared to the prior one? What makes you say that?
>
> E: They had three babies to a small space. They just don't have, like all the equipment. What you guys have. So, you all made more bed space. I guess. They really didn't have private rooms. Everything is, you know, kind of the babies are all together, grouped together. Where here, you all have it separated with a little more privacy. They had the curtains up, of course. But you get a tiny little triangle of space versus, a little more spread out here.
>
> I: So, tell me about your experience so far with her being here in the NICU specifically.

> E: So, when we got here, they put us in the conference room and told us that the NICU doctor be out in just a little bit. I don't think that there can be a more wonderful person to kind of calm your nerves and just make you feel at ease. So, she just told us every little step that they were doing and that everybody was coming in to evaluate or just to make sure and get her settled and comfy and that she would let us know the results of everything ‘cause she had to have the cardiologist team and come look at her. She had, I guess, maybe the people that work on the team that was going to do the surgery. Everyone had to come in and check her. When she came out of surgery, one thing that I absolutely loved is that the entire team that was in there with the surgery came in and they did a report in front of us. So, we were able to hear what happened during the surgery and before they actually came in, *** the surgeon personally came in and told us, you know, she did well for what all she had through the surgery and just gave us a little report before they came in and just let us know that they had trouble with her breathing tube because her airway is so small. So, the one size was too big and then the next one was too small. She was in between sizes and just let us know that he got the fistula corrected. But he didn't want to take the chance. He thought that he could get the esophagus together, but he didn't want to put any added chance with the breathing tube of it having any damage. We've just been recovering and gaining weight since.

Emily seemed very appreciative of the care she had received in the Level IV NICU. She was able to describe the surgeries that her baby had received and discussed the need to recover from the initial surgeries and gain weight. Emily’s baby would need to recover from these surgeries and grow before the cardiologists could repair her VSD. When asked about her typical day in the NICU, Emily was very detailed in her daily mothering occupations as evident in the following excerpt.

> E: I get up in the morning. I stay in the sleep rooms. So, I get up and then pump and then you have to wait your turn for a shower. And then once you get showered and ready, I put everything into my locker that's here. And then you have to clean up the sleep room, take the linens off, just get everything cleaned up and then come in, go eat breakfast downstairs and then come and see her. And then morning times when the doctors do rounds, usually the nurse will update you before the doctors come around, they do a little more specific. They let you know what changes are going to happen for the day, if there's any tests to be done. They offer the *** breast pumps here at the bedside, so I don't have to leave. And then the cafe, of course, is downstairs. So, you don't often leave the hospital. You can just eat here. So, lactation. You get a diet. So, you get like your food pretty much paid for. Which is awesome. And then we just do snuggles as much as possible. The nurses are worried about what you do as much hands on as you want, changing the diapers, giving the baths, changing clothes, taking their temperature. Just anything that you want to do, they'll allow you to do.

> I: And I know having a baby in the NICU is a lot different than having your other children. Do you feel like you're able to still provide all the mothering activities and tasks to her as you have with your other ones?
>
> E: Yes. Besides not being able to physically breastfeed. But yes. Yes. I'm able to hold her, bathe her and. Yes. The hardest part of the whole thing is having to separate, you know, being with her majority of the time and then not having that time with my other kids is probably the hardest thing. And then not being able to be here and see her and hold her *** when I am at home with my other children.

Emily discussed the separation between her children at home and her baby in the NICU being difficult. Emily lives 65 miles from the hospital; therefore, she utilized the sleep rooms that the hospital provides for families who are unable to sleep at the bedside of their babies. Her husband works full time and was able to relieve Emily on the weekends so that she could spend time with her other children at home. This separation between her children was difficult especially because Emily and her baby had been in the NICU for 49 days at the time of the initial interview. Emily's baby received OT services. In the next excerpt, when asked about her experience working with OT, Emily was very open about how it has helped her baby.

> E: I already see improvement with the hand therapy. And then you guys just talking about how to hold for positions and for strengthening her. So, it's things that I wouldn't think. So, it's been really great because it's not something that you think about. You're just thinking of the simple things like not just simple things, but the necessities like her breathing and going through the surgeries. And like the big picture, and that's where, you know, occupational therapy has come in and said, oh, her hands need this and her position of her head needs this and things that I'm not thinking of you guys have thought of.

Emily's experience with OT highlighted the therapy interventions directly related to her baby's developmental needs. When asked about her experience with mothering occupations, Emily was able to discuss in the following excerpt how the nursing staff supported her in these activities.

> E: That's where we talked about the nurses and them allowing you to do as much as possible. I love that every single nurse like when it's time to do the touch times offer to let you do the temp and diaper changes and as much as you want to do. They also very much push for you to hold as much as possible, and bathe, to do all those things.

In summary, despite the medical complexity of her baby, Emily was very open and honest in detailing her experience of her pregnancy, delivery, and her baby's admission to the NICU. She often spoke about prayer and her faith as playing a role in her positive and hopeful outlook for her baby. Emily often appeared anxious when being away from the bedside during the interviews, which was evident by her looking away often, gazing at the conference room door, and avoiding eye contact. Prior to the second interview, Emily's baby had increased respiratory needs and was in respiratory distress the night before, which may have affected her participation in the interview. Even with this medical set back, Emily was able to lightheartedly exclaim that "in between *** the NICU and Jesus, your baby is gonna be fine!"

Participant #3 Rebecca. Rebecca is a 19-year-old White mother who delivered a baby boy via cesarean section at 30 weeks' post menstrual age. She experienced severe preeclampsia at 29 weeks' gestation, which resulted in her hospitalization at the birth hospital. This hospitalization was her first pregnancy. Rebecca earned a GED and is unemployed. Rebecca was open about her own medical needs when discussing her pregnancy and delivery experience (I = investigator R = Rebecca).

> I: Tell me about your pregnancy and delivery experience.
>
> R: The pregnancy was good until 29 weeks. I ended up finding out I had severe preeclampsia and within a week, finding out I was having him. I went to the hospital for high blood pressure the Tuesday I found out. And then on the 11th, that Friday, I went to the hospital again and end up having him Saturday morning at 8:28. I had a classical C-section, but instead of going from the belly button down, it was from the top of my stomach all way to the bottom because my gallbladder was rupturing, and my liver and kidneys were failing. But everything turned out OK.
>
> I: After he was delivered, did he go straight to the NICU at the delivery hospital?
>
> R: Yes. He went there and they waited because he was born within 30 minutes of the surgery. But my surgery was another 2 hours. So, they didn't want to transfer without me seeing him first. And they were waiting for the ambulance to get there. So, they let me see him. And as soon as I saw him, when they woke me up, they transferred him.

Rebecca discussed how she did not remember many aspects of the delivery because of her own medical needs. She also described not recalling how her baby boy looked because everything was happening quickly, and medical devices were occluding her view of him. Since the birth hospital was unable to provide the medical care her baby required at birth, he was transferred to another hospital's NICU which was a two-hour drive from her home. In the following excerpt, Rebecca revealed how her baby required transfer to the NICU from the birth hospital, the distance of her home from the NICU, and how COVID-19 impacted parental visitation.

> I: So, he wasn't admitted to the NICU at the delivery hospital, he had to be transferred?
>
> R: Yeah, he was waiting, but they had him over there with Dad waiting for me to come out.
>
> I: And then once he was admitted to *** the other NICU, you were able to go and stay with him or did you have to go home?
>
> R: I had to go home. And it's a two-hour drive every day. So, I had to go every day. And they only, here, they let the, you know, dad and mom switch out. There they would only let one parent per day. They wouldn't let you switch out. So, we had to take turns. ***Due to COVID-19.

Rebecca discussed how the drive to the NICU was long, but that she was able to visit him every day. At some point during his stay at the NICU, he developed necrotizing enterocolitis. This diagnosis required surgical intervention; therefore, he was transferred to the Level IV NICU. Her baby was also diagnosed with anemia and intestinal bacterial overgrowth. The Level IV NICU is 46 miles from her home, which correlates from anywhere between one-hour to two-hour drive, depending on traffic. She discussed how this experience has affected her ability to be at the bedside. In the following excerpt, Rebecca noted how frightening it is for her baby to need surgery.

> I: Can you elaborate on what your experience has been having your baby admitted here?

> R: When he was first, when he first came here? I was, you know, I knew he had NEC and stuff, and I was, I was scared. So, what's going to happen so like with severe case he's going to need surgery. And he had a severe case where he needed surgery. So, I was very scared.

Rebecca was able to explain her feelings of her baby requiring surgical intervention for NEC. She became tearful when speaking about her thoughts that he may not make it through the surgery because he was so little and fragile. The distance between her home and the hospital appeared to be a barrier to her bedside presence. She appeared to be nervous when talking about how often she is at the bedside as she stated she tries to visit daily, but she was actually present 1 day to 2 days a week.

Rebecca was asked about a typical day for her and her baby when she is able to be at the bedside. Because this pregnancy was her first baby, it was interesting to hear how she was learning to become a mother in the medical environment of the NICU. In the following excerpt, Rebecca was able to discuss which mothering occupations she was doing with her baby.

> I: So, tell me about a typical day for you and your baby here in the NICU.
>
> R: Typical day. Just me coming in the morning. And he usually would be. He's usually an early bird. He would wake up pretty early. We'd get him out. Just hold him and snuggle him. And then I would do, well, when they did the hands-on care time and stuff. We were starting to like, sit him up and let him bounce a little. And we were just try a little new things and do paci dips and stuff like that. So, it was always fun to be able to see something new and see him grow and improve.
>
> I: And so, tell me, I know you talked about holding and snuggling and doing the paci dips. What other mothering or caring activities have you been able to do?
>
> R: I was able to do the kangaroo and chest to chest. He loves it. And really, that's all we were able to do at the time because he was still underage and stuff. They said he needed to rest but the best places to be in the parent’s arm and stuff. But he, we really just, we were just now trying out new things with him and then he ended up getting sick again and then we had a delay it.

Rebecca seemed frustrated when discussing the need for a second surgery. She also stated that he would need a third surgery to reconnect his intestines, which would prolong their admission.

They had been admitted to the Level IV NICU for 2 months at the time of the initial interview. Rebecca stated that her son was receiving PT and ST. In the next excerpt, Rebecca stated how therapy services were helping her and her baby.

> I: So, describe your experience of working with therapy.
>
> R: I love it because we are always trying new things, obviously. And now he's, umm, he's able to move his head by himself. Like turning it and stuff. And he's only 3 months. But he was born 2 months early, so that's pretty good for him because he's pretty much from his due date. So, it's like only a month. He's smiling a lot more. We said he loves to sit up, like sitting up and then we still do paci dips sometimes. And what else? Oh, he loves, he now, he loves his little balls and like his toys, he loves playing with those in the swing. He's really happy with it now.
>
> I: So, during your physical therapy appointments or sessions that you've had with her, mostly they're focusing on the baby?
>
> R: Umm-hmm.
>
> I: Can you tell me about any time that they've talked about mothering or caregiving to address any needs that you specifically have?
>
> R: Yeah, they yeah, they'll tell me, they'll ask me little things, what I'm comfortable with, but they also tell me what's good for mom and baby. And a lot is basically mostly skin to skin, like holding him up just as head to chest to keep his head support. And he's, you know, this kind of like tummy time for him. And they've always been like, they won't make me do anything that I'm uncomfortable with. But they, they're right there beside me helping me through it. And they yeah, they just basically skin to skin on the chest and just feeling that connection. And they're always right there. Helping me. And I'm like, is he going to like it? Do some babies not like it, but as soon, every baby loves it. And they have talked me through it and got me through that. And I was just like scared to hold him at first because he was so tiny. And I'm like, I don't want to hurt him. They are like, you are not going to hurt him. It's fine, but I put him on my chest. And that was just, it was perfect from there.

In summary, Rebecca is a young, first-time mother in which distance from the hospital has posed a challenge to her bedside presence. Her premature infant experienced NEC, and the need for multiple surgeries have increased their length of stay. Despite these potential barriers to participating in mothering occupations, therapy services and medical staff have helped her learn

to care for her baby. Rebecca always had a positive outlook when discussing her experience of having a premature infant admitted to a Level IV NICU.

Participant #4 Erica. Erica is 35-year-old Black, first-time mother. She has a bachelor's degree and works full-time. Her baby was delivered at 32-weeks' post menstrual age via a vaginal birth. When asked about her pregnancy and delivery experience, Erica discussed that which happened in the following excerpt (I = investigator, E = Erica).

> I: Tell me about your pregnancy and delivery experience.
>
> E: Pregnancy was really easy. Not a hard pregnancy at all. Barely noticeable. So, no issues with the pregnancy and delivery, delivery, minus that she came early, was really simple and easy.
>
> I: So, no complaints. What caused her to be delivered at 32?
>
> E: They do not know but my water did break.
>
> I: OK. Blood pressures and all that was fine?
>
> E: Everything was normal.
>
> I: Good. And it was a vaginal delivery?
>
> E: Yes.

Erica seemed to lack information from the doctors as to why her baby was born at 32 weeks' gestation or she was not ready to talk about it. When prompted about her experience with being admitted to the NICU, Erica seemed to have the impression that it was solely because her baby was premature. During the following excerpt, Erica was asked to discuss her feelings of having a premature infant admitted to the NICU.

> I: And then at what point did they take her to the NICU?
>
> E: When she came out. They had her, you know, tried to, I guess, like, warm her up next to me. So probably like within 30 minutes she was taken to the NICU.
>
> I: What prompted the NICU admission?

E: Being that she was so premature, 32 weeks premature. I guess that's automatically a NICU stay and umm basically because of that. Yeah.

I: Was she breathing OK at that point?

E: She was breathing okay. They felt like it was a little off. They did give her oxygen when she was in a bed and they were working on her.

I: And then the NICU was at the birth hospital.

E: Yes.

I: And at what point was she transferred here to *** the Level IV NICU?

E: She stayed there approximately 6 weeks and they transferred her here.

I: Because of a medical decompensation or . . . ?

E: Just no progress overall. And they felt being that she was her so-called corrected age, that she should have been stable or have progressed by then.

I: What were your thoughts about coming to a different NICU?

E: They didn't say, they say was possibly she would, you know, have said they didn't know what was wrong with her, basically. So, they just stated that she's going to move to a facility that specializes in, I guess, just children overall. So, they would be better equipped to figure out what's wrong with her.

It was evident from the initial interview that Erica appeared to have an incomplete story of why her baby needed an admission to the Level IV NICU other than just being premature. Her baby had been diagnosed with BPD, IVH Grade 1, pulmonary hypertension, and hemiparesis of right diaphragm, which she only noted the BPD one time during the interviews. Due to the BPD and surgical intervention for hemiparesis of right diaphragm, her baby had been admitted to the Level IV NICU for 4 months at the time of the initial interview. Erica lived 30 miles from the hospital, and she was able to visit every day. She was able to work from home, which also allowed her to visit every day.

Erica's baby received OT, PT, and ST services. Because Erica could work from home and lived close enough to the hospital to be present every day, she was active in her baby's care. In the following excerpt, Erica was able to describe working with therapy services and performing mothering occupations.

> I: Can you describe your experience working with the therapy services?
>
> E: Well, the various therapy, therapists that she does get, which is the occupational, speech, and physical therapy. I do see that she has made improvements on certain things. So, I definitely find it beneficial. And they do teach me to do certain things as they say, homework, like for the weekend when they don't work with her. So.
>
> I: Because you do get the OT, PT, and ST, can you tell me any differences between the three on what they've been teaching you?
>
> E: So, for occupational is more so rolling over, learning how to prop herself up, sit up. That seems like more doing with her muscles, grasping and such things. As for speech, they are helping her with the whole oral, sucking. Getting back to taking the pacifier and on the roads to drinking out of a bottle and the occupational is. I will say a combination well it will be definitely be. It seemed like it would do with the occupational, yeah, physical, excuse me, physical has a lot to do with occupational as well. Physical is more so like moving fine moving of like the muscles and stretching as well.
>
> I: Has any of the three services spoken to you about achieving mothering activities or how to become a mother? So, like the dressing, bathing, diapering.
>
> E: No.
>
> I: Okay. Who has done most of that for you while you've been here?
>
> E: I definitely do it myself. I like to be hands on when I'm here with her. So.
>
> I: And what do you feel like the most bonding thing between you and her have been?
>
> E: Well, just holding her and just talking to her. Because there's you know, there's no breastfeeding, which I would have liked to do. Being she's still on feeding tubes. So just trying to bond more of the best way and by holding and just talking to her.

Despite discussing the adaptations to mothering occupations, such as bathing due to the medical needs of her baby and the required medical equipment, she appeared confident in learning and performing care, which was evident in the following excerpt.

I: So, describe your experience of caring for your infant while, here in the NICU.

E: Not what I expected, it being a first-time mom. So of course, the alarms go off, so I wouldn't have to pay attention to that at home. So, here is just more. A little bit. It was a stressful interaction with her. So. Yeah.

I: Are you participating in all of the mothering activities?

E: Definitely. Yes.

I: OK. And what's been hard about that?

E: Just for when she's taking a bath. Of course, she's not home. So here the baths are lined with plastic. And she slides down in the bath. Then she has the feeding tube, so you have to pay attention to that. You've got to monitor it. Don't get wet. Then her oxygen tube. You got to you know, that may get in the way. So, you've got to pin it up. So of course, I wouldn't have to worry about this stuff at home.

I: And what has the staff done to help you navigate all of that?

E: If I need help, they're there to help.

In summary, Erica discussed her experience of being pregnant, her early delivery of her daughter, and being admitted to a Level IV NICU. Compared to the other participants, Erica had the longest admission at the time of the initial interview. Despite the prolonged admission, Erica was able to be present at the bedside daily due to the ability to work from home, which afforded her the time required to learn how to perform mothering occupations for her premature infant.

Participant #5 Crystal. Crystal described herself as a 28-year-old Black mother of two. She has a 9-year-old daughter who is being cared for by her sister and other family members while she is at the Level IV NICU with her son. Her son was born prematurely at 23 weeks, 4 days post menstrual age. He was the earliest born infant of all the participants. Crystal has an associate degree, is currently taking college courses, and is not employed. She lives 25 miles from the hospital and utilizes the sleep rooms at the hospital occasionally to be able to spend

more time with her son. Crystal was able to discuss her lived experience of having a premature infant in a level IV NICU in the following excerpt (I = investigator, C = Crystal).

> I: Tell me about your pregnancy and delivery experience.
>
> C: My pregnancy was OK. I had a few complications where I was bleeding. Well, my delivery or my OBGYN experience was horrible. My experience at *** the birth hospital, it was okay. I had a great nurse at *** the birth hospital, and then I was transferred here.
>
> I: And that was at 23 weeks?
>
> C: That was at 22 weeks. I went into labor the next week at 23.
>
> I: Did he come vaginally or C-section?
>
> C: C-section because he was trying to come breeched.
>
> I: Then how long were you in the hospital after that?
>
> C: I was in labor 3 days then after that 2 days after I had him.
>
> I: And how soon were you able to see him?
>
> C: Umm, I saw him right after I had him. He was on the table.
>
> I: Okay. And did they take him straight to the NICU? What happened right after he was born?
>
> C: They took him straight to the NICU and hooked him up to monitors. And then after they got him situated, I was able to go back up to the NICU and see him.
>
> I: And that was at *** the birth hospital's NICU?
>
> C: Yes.

When asked about being admitted to the Level IV NICU, Crystal was able to explain her experience with the medical staff and how she felt about being transferred from the birth hospital's NICU. The following excerpts highlight her experience.

> I: And then how long was he in *** the birth hospital's NICU before you transferred him here?
>
> C: Five days.

I: So how did you feel about him being in the NICU? Were you prepared?

C: No. Cause he was early, so I didn't know what to expect.

I: Yeah. Did the doctors once they decided that you were going to be delivering him early, did they prep you at all about what to expect once he was born?

C: Yes, several times.

I: Did it make it any easier?

C: No. I actually got tired of him coming to talk to me because he just kept saying something about, he only had about a 17% chance to live. Do I want to continue to go through it and blah, blah, blah?

I: So, what was it like when you learned that he was coming to this NICU?

C: I guess scary because he was coming because he had to have surgery. And then after he had the surgery, he started to do better. Well, he had his ups and his downs, but he's gotten better.

Crystal's baby had developed spontaneous intestinal perforation (SIP) while in the birth hospital's NICU which prompted him to be transferred to the Level IV NICU for surgical intervention. He was also diagnosed with ROP, fungal sepsis, and apnea. In the following excerpt, when asked about her experience of being in the Level IV NICU, Crystal was able to discuss how she has been performing mothering occupations.

I: So, what has it been like having him here in the NICU?

C: I mean, I guess I kinda like this NICU better because of the rooming and the space I am able to spend time with him. At the other one, they were smaller. It wasn't that much, I guess, privacy area. This one is bigger. I get to spend more time with him.

I: Speaking of spending more time, tell me about a typical day for you and your baby.

C: When I wake up, I come get him up. I let them do his 8:00 care after he gets his 8:00 care, I'll come hold him for like 3 hours or 4 hours. Then I put him back and let him rest, then I come back at night and give them a bath and hold him again and play music for him.

I: And do you feel comfortable doing the mothering tasks with him?

C: Yes.

I: What was the most challenging part of that?

C: At first, it was changing his diaper because it was difficult, changing it with all of the wires and cords. But now that he's gotten bigger, it's easier to change him and do things with him. As of now, I don't feel like anything is difficult.

Crystal's baby received OT and ST at the time of the initial interview. When asked about working with therapy services, Crystal was able to discuss her experience. In the following excerpt, Crystal states which therapy has done to help her.

I: Can you describe your experience of working with therapy services? I believe you've been working with occupational therapy and speech therapy.

C: It has been great. Just motivates me to help him more to get further along to get discharged. And to help him to get better on his own than to depend on support.

I: Great. Have they addressed mothering skills with you or just baby skills with *** your baby?

C: Both. And I am watching the discharge DVDs or whatever the channels.

I: Good, the education, *** required discharge educational videos?

C: Yeah.

I: And has anything changed throughout your admission that helped you feel more like a mother to *** your baby?

C: Oh, and they let me care for him more and do the hands-on and change things and help out with him more.

Overall, Crystal's presence at the bedside allowed her to become comfortable in performing mothering occupations with her premature infant. Despite her premature infant being the youngest baby in the dissertation study, she was able to perform his care with the help of the NICU staff. Crystal verbalized during the follow up interview that she did not enjoy talking to people, which was evident in her shy demeanor while talking about her lived experience.

Participant # 6 Amy. Amy is a 27-year-old Black, first-time mother. Her son was born at 25 weeks' gestation. Amy lives 28 miles from the hospital, and she travels back and forth from home and the hospital daily. Amy has a bachelor's degree and works fulltime as a schoolteacher. Amy was able to discuss her pregnancy and delivery experience in the following excerpt (I = investigator, A = Amy).

> I: I would like you to tell me about your pregnancy and delivery experience.
>
> A: I had to go to the hospital, and I was admitted that night because I was on a blood pressure monitoring program through *** my insurance and the nurses, you know, they became concerned. They reached out to the doctor who was on staff at *** the birth hospital at night. And she told me to just come on in. And I managed to keep him in for another week. But I forget the name of the doctor. And so, of course, it made me so emotional. But I just I agreed to it because I didn't want *** to lose the baby. And so, on May 30th at like 2 something in the morning. He was here. And it's just been a stressful, emotional journey.

Amy discussed how scary her delivery was not only because she had never had surgery before but also because she was alone. The father of her baby was not a consistent figure in her life, and her mother was often unavailable due to her own responsibilities. In the following excerpt, Amy discussed her delivery experience.

> I: And so, the delivery, was it vaginal or C section?
>
> A: C section.
>
> I: OK. And tell me about that whole process.
>
> A: So, I was just laying there nervous as heck, and I had to call my mom, and I'm like I'm going to have him soon. She was just so excited for me. But I don't know why I thought she was going to come in the middle of the night with me. But she didn't. And so, I was essentially there by myself other than, you know, the medical team. And so, when it was my turn, I was trying my hardest, to like, overcome the nervousness, but I couldn't because I've never had surgery before, let alone giving birth. Plus, he was super early with 25 weeks. So, it's just a lot. So, the next thing I know, they were starting the surgery, and I can't even tell you what time it was and how long it took. But the next thing I knew, I heard a cry. It was a very tiny cry. And I was like, is that is that my baby? And then the nurse who had helped me the whole time. Yes, that's him. So, I didn't see him until the NICU people had gotten him situated. And they wheeled him around up

> there a little bit. And I looked up because I could barely see him, but because he was in, you know, the little what is it, the incubator. He was in that. And I was just amazed.

When asked about having a premature infant in the NICU, Amy stated she was unaware that he would need to be admitted to a NICU as no one had prepped her for the initial admission directly after birth. Amy discussed these feelings in the following excerpt.

> I: And so, what were your initial thoughts when you learned that he would be transferred to the NICU after the early birth?
>
> A: So that night I was admitted into the hospital the very first night the neonatologist came to speak to me. And it was the first time I ever knew of any of this. But before then, I knew that there is the high-risk specialist, like there's no way we would feel comfortable delivering you past, if I'm not mistaken, 36 weeks, 37 weeks, and so for it to happen way earlier than that. Course, I was caught off guard and so unprepared for everything, but I didn't even know what was considered a preemie like the earliest birth is like just everything was new to me. So, it was a man *** neonatologist who was the older man and he was very kind. And he was saying, you know, we've taken 25 weekers all of the time. You know, he's not the first one. And he certainly won't be the last. And so, I started laughing when he said that, but it just made me feel more comfortable. But I was still nervous, of course, and he just went through everything he told me, like, not necessarily what to expect with a 25 weeker. But, you know, that they are trying to do all these different things to take care of the baby. But I can't really remember everything that was said. But that's basically what he was talking about.

Amy's baby stayed in the birth hospital's NICU for 2 weeks before he was transferred to the Level IV NICU. Her baby developed a bowel blockage due to meconium plug syndrome and small bowel perforation, which required surgical intervention. He was also diagnosed with BPD and ROP. Amy discussed this transfer in the following excerpt.

> I: How long were you in that NICU before you transferred to this NICU?
>
> A: Was it? Two weeks, 2 weeks or close to it.
>
> I: OK, and what happened to him that made him need to come here?
>
> A: He wasn't having bowel movements and so his neonatologist over there. He said that we think it's pretty serious and we should, you know, get somebody who's further trained and qualified to take care of him to look at it. Because he said something like *** the birth hospital is like an adult hospital. It didn't, you know, have everything that a preterm baby like him needed. And so, yeah, I just had to agree to let them transfer him here.

> I: And so, it was for a surgical evaluation, or they didn't even talk about surgery at that point?
>
> A: So, I don't know if it was surgery at that point. I just knew that they didn't have the equipment to look at him and see exactly what was wrong. But when I was getting ready to come up here, there was a doctor, I guess he was on staff that night who said that they were going to have to open him up and basically look around to see what was causing the problem. So that's when I knew that he was going to have surgery. And of course, I'm all emotional at that time because I'm like, surgery, when did we get to this point?

Amy was very emotional during the interview discussing not only her pregnancy but also the delivery experience due to her baby being premature and requiring a high level of medical and surgical care. Amy also experienced the loss of her sister unexpectedly who was one of her biggest support systems. She discussed this traumatic loss in the following excerpt.

> I: Is there anything else you would like to further discuss regarding your experience of having a premature infant in the NICU now that you've had some time to think about our first interview?
>
> A: So along with me, you know, having a preemie. I recently lost my sister on the Fourth of July unexpectedly, and that just added to the stress and the, you know, the grieving and everything else that I was going through with my son and the NICU, but. This is kind of like I feel like I haven't really had time to grieve her loss because I'm still grieving the loss of, you know, my perfect pregnancy, birth story, etc. It's a lot to take in. I'm going to seek therapy soon. But right now, I'm just trying to. I don't even know it's kind of like gather my thoughts and accept that she's no longer here. But, yeah, it's just a lot.
>
> I: Was she a good support for you? What kind of role did she play in your life?
>
> A: So, she is my older sister. I considered her my best friend. She was one of my biggest supporters. I could always reach out to her, ask her questions, advice because she was a mom and, you know, she had two kids. So, I could easily ask her advice or ask her questions about pregnancy and what they expect and things like that. And just with her not here, I had to get adjusted to not being able to just reach out whether it's through text or call. So, yeah, it is definitely a big loss in my life. I feel it every single day.

Even though Amy voiced grieving the loss of not only her sister but also a normal pregnancy, she appeared to perk up when asked about mothering in the Level IV NICU. She spoke about the support from not only the nursing staff but also the OT. Her son only received OT services at the

time of the interviews. In the following excerpts, Amy discussed her experience of mothering in the Level IV NICU.

> I: Describe your experience working with therapy services. I believe you get occupational therapy. Do you also get physical therapy and speech therapy?
>
> A: But so, I only receive occupational therapy at the moment and so far, it has been a positive experience. I mean, the therapists that I've met have been helpful and teach me ways to comfort him when his nurses are doing like hands-on care. So, I would say it's a positive experience.
>
> I: And had they used specific terminology like mothering activities or teaching you how to perform mothering tasks or if they've just been focusing most on the baby?
>
> A: So, I forget her name. But when I first was over on the A side, she was teaching me how to do like the mouth care and oral care. Stuff like that. And she was telling me things that I could look forward to when he got older and came to this side, which is the swing side, as far as like helping with changing the diapers and checking his temperature and eventually doing bath time, so bath time is actually something I'm going to do today, so I'm really looking forward to it.

In summary, Amy experienced a lot of grief between having a premature birth and losing her sister. She often expressed being emotional and stressed when discussing her experience of having a premature infant. She was very forthcoming of her feelings. Even though she had limited support from her family, she acknowledged the assistance she received from the medical and OT staff in helping her learn how to care for her son.

Participant #7 Michelle. Michelle is a 31-year-old, Black, first-time mother who gave birth to her daughter at 26 weeks and 2 days due to complications with her placenta. Michelle earned a bachelor's degree and was working fulltime as a flight attendant. Upon learning she was pregnant, she decided to take maternity leave early since she believed to have a high-risk job. Michelle lives 30 miles from the hospital and visits daily. She was very open when discussing her experience with pregnancy and delivery as presented in the following excerpt (I = investigator, M = Michelle).

I: I would like you to tell me about your pregnancy and delivery experience.

M: OK. I had a pretty I would say a rough pregnancy towards the end. In the beginning, I had some issues with my OBGYN. I was noticing things that I just felt weren't normal. I know you are not supposed to compare yourselves to other women because every woman's journey is different, but there is a girl who is a little taller than me, but my same build, same size, same ethnicity. And she was showing so much more than I was. My daughter was supposed to be born July 18. This young lady's daughter was supposed to be born July 20th. And she just had surpassed me in her physical appearance. So, some of the things that I was noticing for myself was I had actually been on leave *** from work. I'm a flight attendant. And I'd actually been on leave from my job about two weeks after I found out that I was pregnant, because since I fly, it's a higher risk. You come in contact with a lot of people, radiation and air, things like that. And we were entering flu season, so I took maternity leave early. And then because I was considered high risk, I ended up being on short term. I was well into being five months pregnant and I still had my abs and everything. I was completely flat. So yeah, that was some of the things that, that I experience in my pregnancy. So, what happened was within excuse me, I think the last time I interacted with this old OBGYN was around March 1st. I'm going to say somewhere around there. And I subsequently had an appointment with a new OBGYN March 5th. And he immediately sent me to a fetal specialist. And I, because of COVID, the fetal specialists wanted me to go live into the hospital, not because of COVID. I'm gonna explain. But the fetal specialist wanted me to go live in the hospital until it was until I was 30 weeks at that time, I want to say I was around 20 weeks or 21 weeks. Somewhere around there. And I fought with them a little bit about that because COVID had broken out. And at that time, I just, we didn't have an understanding of it. Medical staffs were short on the supplies they needed. I just didn't feel comfortable. I could social distance at home. So, I made the decision not to go live in the hospital. Also, with that being said, the fetal specialist told me that my daughter would need to be at least 400 grams in order to be pulled out safely. She was still, like I said, I was 250 at that time where I should have been well over four, which is one pound. I was ridiculously low. And so, knowing that risk, that was with the intermittent blood flow, basically, my placenta was doing this. Excuse me, like an irregular heartbeat. And there was a chance that she could die in the womb, which was more stress. I ended up sending my body into a shut down, kind of like what a stroke patient has, I shut down the complete right side of my body that I had to be carried into the hospital because of all the stress I ended up being under. So finally, when I was at the agreement that the fetal specialist and the OBGYN and agreed with me, we all came to that I would drive to the fetal specialist every day and make sure her heart was still beating because I just couldn't go live at the hospital at that time. I just I couldn't do it. Well, when I hit twenty-five weeks right at the end, whenever that Friday was, I guess twenty-six and six excuse me, twenty-five and six. They told me no, take my butt up there on Monday morning. So, Monday morning ended up being twenty-six and two. And I was supposed to actually stay until I was 30 weeks and the plan was at 30 weeks to pull her and she came that day.

I: Was it vaginal or C-section.

M: Classical C-section.

I: And so, tell me about that delivery experience.

M: By that point, I was so, I wasn't even stressed anymore. I had pretty much gone through so much from January until April, just with the pregnancy and stuff like that. Then by that time, it was time to give birth. I was like, OK, let's just do it and the OBGYN that actually delivered my daughter just gave me so much confidence just in the fact that I had been heard from the first moment I met him that I was comfortable. He said, we're going to have to pull her. It's for your safety and hers. And I was just comfortable. Even though in that situation, you know, all hell was kind of breaking loose. I was really comfortable. It was a smooth delivery. I knew they knew what they were doing. I knew he knew what he was doing. But my pregnancy was fine. It was fine. I mean, my delivery was fine.

Michelle was being followed by the fetal specialist who had prepared her that her baby was most likely going to be born early. Michelle stated she was prepared for the early birth but did not expect her to be born at 24 weeks' gestation as they were hoping for at least 30 weeks' gestation. When asked about her experience with the NICU, she spoke about the specialized care her baby required. Her baby was not only premature but had been diagnosed in the NICU with small for gestational age of weighing less than 500 grams, multiple organ failure, PDA, and BPD. The next excerpt highlights this experience.

I: What were your initial thoughts when you learned that your baby would be admitted to NICU?

M: You know, I knew that. I mean, that's what I would expect coming at, you know, 3 1/2 months early. So, there weren't any fears there. The only thing was and even, too, I think in that moment I had accepted she'd be there at least until term, which would be July 18. And now we're past that.

I: What has your experience been of having her here?

M: I love it here. Well, the reason why we got transferred here is because she needed more like intimate care and everything that the other hospital was giving her that they were giving her was based on what doctors here were saying, and I know a lot of the doctors actually do both locations. But to be here and have the pulmonologist down the hall, you know, and stuff like that is you know, it's important she gets care faster and stuff like that. So. And also, the other hospital had been talking to me that she would need

> this PDA surgery eventually. And so, we kind of knew she'd end up here anyway. And then as soon as we came here, we had the surgery within days.

Michelle was able to elaborate on the different medical specialists that her baby was receiving in the NICU. When asked about a typical day for her in the NICU, Michelle spoke about mothering occupations she is able to do. In the following excerpt, Michelle discusses caring for her premature infant.

> I: So, tell me about a typical day for you and your baby in the NICU.
>
> M: We do lots of kangaroo time. And, you know, I think any mom, you're nervous taking care of a baby. I have a fear of not wanting to hold babies until they're six-month-old, like Cabbage Patch size. And I got a preemie. Look, you look at my draw. What is it? The draw of the cards. Right. I got a preemie that wasn't even a pound. So being here and getting to see how all the nurses handle the baby and take care of her, it gives me confidence and reassurance, like, OK, you can be a little firm without feeling like you're gonna break her. I don't need a nurse to help me, do, you know, things that you would want to do anyway. But with more wires and stuff, I mean, you know, I feel comfortable. So, my day here is I come in, I can change diapers, I can do temperatures. I can work her bed completely. The incubator bed, the cribs. I can do everything. Yeah, I can take care of her as if we were at home.
>
> I: Good. And so, you mentioned kangaroo care, temperature taking, diapering. Tell me how that evolved, how you evolved in your ability to care for your baby in that way?
>
> M: Very slowly. My daughter was like I said, wasn't even one pound, so it was very scary. And that care actually started at the other hospital. Them just saying you have to give it a try. We won't rush you, but you have to try it to be coming here and being like, no I can do it. And then especially having my primary nurse here, she's more vocal. She makes it to where I don't have to say, can I do this? She goes, come on. Come on. Hey, hey. You know, and so here is where I can say it blossomed more just because of her helping me feel like, one, I'm not in the way and, two, just making sure that, you know, I'm included. So, it's evolved that way to where now I don't even, I let her take care of her other babies, but I know she's listening out for mine, you know, to where I can just sit in there for 6 hours. And she, I would hope, she feels confident that I've taken the baby's temperature, her diapers been changed, that at 4:00, you know, everything's been done. Like I'm monitoring her stats, like I can pretty much do everything and that that's how it's evolved. I, I would never, but I could probably even work the respiratory machine at this point. We've been here a while.

Michelle spoke about the length of time she has been in the NICU. At the time of the initial interview, Michelle's baby had been admitted to the unit for 1 month and 2 weeks. She spoke

about how primary nursing had been paramount in her ability to care for her daughter while making sure she is competent in managing the medical equipment. She was also asked about working with therapy services, which at the time of the interviews was only PT. Michelle discussed her experience with PT in the following excerpt.

> I: So, your experience working with therapy services, tell me how that's been going.
>
> M: She's turning her neck to the left completely by herself. It's great. You know, we stretch out her legs and her toes. Physical therapy has been really good. I didn't even realize honestly until *** the PT told me that that was something I should be doing, you know. When I met her back in June, I had no idea. So just to have a leg up on that is great. We are reading the books, listening to music, singing and talking, all types of things, holding her, cuddling her. *** The PT is a big advocate for all of that. I switch my books out in the library every week because of her. You know, I don't even know we had a library until *** the PT told me so. She makes sure that *** my baby gets her time. You know what I mean. So good.

Overall, Michelle had a difficult story to tell in the beginning, but also was very open about how the resources and medical staff have helped her along the way to care for her premature infant. Michelle's account of how she evolved as a mother to a premature infant was notable for strength and determination. She was able to speak about how support from her husband allowed her to feel secure in her abilities to become a mother in a medical environment. She was also grateful that her employer gave 12-months of maternity leave for its employees. This is a great benefit that not all mothers have so that they can be present at the bedside daily.

Participant #8 Kristina. Kristina described herself as a 33-year-old Black, first-time mother. She has an associate degree and works fulltime. She is married and had been trying to get pregnant for 10 years. She lives 62 miles from the hospital and utilizes the Ronal McDonald House for lodging to be close to the hospital. Kristina was enthusiastic in telling her story of becoming pregnant and of her delivery experience in the following excerpt (I = investigator, K = Kristina).

> I: Tell me about your pregnancy and delivery experience.
>
> K: For the first 23 weeks of pregnancy, it was amazing. The doctors said that I couldn't have kids for 10 years, and they even suggested for me to have my ovaries removed. And I told them, no. I was like, I'm not going to have my ovaries removed. I'm still young. Let's keep trying. So, one doctor said, well, if you lose 15 percent of your body weight, you may be able to get pregnant. Well, one doctor decided to do a DNC to kind of scrape to clean me up a little bit. And 2 years later, I did a keto diet. And 5:30 in the morning, I was in the bathroom laughing my behind off because I was pregnant. Before I could even get the test on the counter, it turned positive. I went to the doctor. I had some blood pressure issues and, of course, a few weight issues. So, they automatically said that I needed to see a high-risk doctor. I was already going on 10 weeks, I found out, and I took a blood test around 10 weeks 5 days-ish, and I found that at 12 weeks I was having a little girl. Pregnancy was going fine. Blood pressure was perfect. My blood sugars were good. And around 23 weeks I went to the doctor and they had me do a urine test and it came back and my sugar was out of control. They said, "You have gestational diabetes."

Kristina sounded excited when describing her journey over a 10-year period of trying to get pregnant. She also discussed how happy her husband was to find out she was finally pregnant. However, she became tearful when talking about why her baby was born prematurely. In the following excerpt, she was able to explain her health issues while pregnant.

> K: I went in on a Thursday afternoon or Thursday morning, I came up here to go to my prenatal doctor. My blood pressure was fine when I walked out. Baby was doing good and I was 24 weeks at this time, by the way. And I left there, and I went to my OBGYN and I got there, and they took my blood pressure. My blood pressure was 161 over 117. And she said, "Do not pass go, go straight to the hospital, do not collect 200 dollars or none of that stuff. Go." So, I went to the hospital and they put me automatically on a mag drip and I got a steroid shot, one of the very first ever steroid shots that I've gotten since I was pregnant. And I was so scared, I didn't know it was going to happen. It was my first pregnancy and I literally thought that I was getting ready to lose my baby, you know? I didn't know what was going on.

Kristina became emotional when speaking about her delivery. She delivered her baby girl at 25 weeks' gestation via non-emergency cesarean section. In the following excerpt, Kristina was able to discuss her delivery experience.

> K: The doctor said that, you know, when she comes out, if she comes out crying, we have a fighting chance. But if she does not come out crying, we might have a problem. And I can remember looking at my husband while they were cutting on me and I had tears in my eyes, and I said what if she doesn't come out crying. And he said, cheese and

> sprinkles. And I said, what is cheese and sprinkles?!? He was like, that is a mess. She's going to come out crying. And I felt the push on my stomach, and I heard, “Wahahaha.” And I was like, is that her? He was like, “That's her.” And they were going to immediately take her down to the NICU. And I said, please let me see my baby. I remember seeing her. And I remember them taking my husband out of the room. But I do not remember getting back to the room. I passed out on the table, but if I had to do it all over again for her, I would.

Kristina’s baby was transferred to the birth hospital’s NICU after delivery and stayed there for a total of 4 days before transferring to the Level IV NICU for surgical evaluation for NEC. Her baby was also diagnosed with a PDA, IVH Grade 2, BPD, and ROP. When asked about her experience in the NICU, Kristina was able to describe how she felt about being a mother in the NICU in the following excerpt.

> I: What were your initial thoughts when you learned that she was going to be transferred to a NICU, tell me how you're feeling about that?
>
> K: I cried. I felt really empty. I prayed a whole lot. I think there was one point that I was praying so loud that the nurse came in and asked me if I was OK. And I said I'm fine. I'm just asking God to keep me and my baby. That's it. You know, I don't know anything about the NICU. I didn't know anything about the NICU. Now I've learned so much, but I didn't know anything about it. And only thing I thought when I hear ICU, adult wise, it's kind of like, OK, they're about the transition, you know, or something is really wrong. And that's the only thing I could think of.
>
> I: Tell me about your experience of having a premature infant admitted to the NICU.
>
> K: I'm so scared. I don't know what to do. I don't feel like my baby has a fighting chance. She's so tiny. They keep telling me, you know, she's not actively dying, you know, and I'm just like all of these emotions were flowing over me. And then on top of that, with postpartum and, you know, PTSD. The doctor called me, and she said, “Mrs. Kristina, we're gonna transfer her to *** the Level IV NICU.” I said, “Well, what's wrong?” And she said, “Well, we think that she has NEC. She has a hole in her intestine and it's building up a lot of gas. And, you know, *** the Level IV NICU is gonna be the right place to take her.” When I got here, my NICU experience has been over the top. I've learned a lot, being a first-time mom and I've changed diapers before. OK. Don't get me wrong. However, if they're poopy diapers, I like to give them back to their mamas. But I've, I've learned a heck of a lot, big words that I just never even understood. And the nurses, they break it down, the doctors, they break it down. I mean, this NICU experience has been nothing short of amazing because I've gotten to watch my baby grow and flourish and to be just a plump, a little plump. This is my little chunk, my big butt. I've gotten that opportunity. So, it's been, it's been great.

Kristina was noted to become excited when portraying her story of being a NICU mother. She often spoke highly of the medical staff and explained how they helped her learn how to care for her baby. In the following excerpt, Kristina was asked about her experience with caring for her baby in the NICU.

> I: Describe your experience with caring for your premature infant.
>
> K: I like to be here during care times. I've learned how to *** work the beds to get her up. I've learned, you know, of course, the right way to change a diaper. I've learned how to put her clothes up from her legs all the way up. I mean, it's a learning experience here. They teach you the things that you need to know before you go home, especially being a first-time mom. Even they always say that the mommy instincts kick in. But you don't know what that is until you're, you know, you're really just doing it. So, you learn a lot. Like a lot.

In summary, Kristina was able to describe her challenges with becoming pregnant, her own health issues that affected her pregnancy, and the premature birth of her daughter. She was forthcoming of her experience with being a first-time mother in the NICU. She applauded the medical staff, especially her primary nurse, with teaching her how to become comfortable in the medical environment. She was also appreciative of OT in regard to learning how to care for her baby.

Themes of the Findings

During the data analysis process, the interviews were read and reread before coding took place. Each interview transcript was coded in the same manner by reading and rereading the data following the initial coding. This process improved familiarity of the data. Different colored highlighters and colored pencils were used for coding the data to indicate similar statements and ideas. A codebook was kept with an index of each color for identification purposes. The process for data thematic developed is depicted in Figure 1.

Figure 1

Process of Thematic Development

Once color coded, similar codes were grouped together to begin forming categories by having the data cut out and placed into piles according to commonalities. These categories included similar statements and ideas from the data (See Table 3).

Table 3

Categories of Codes

	Categories				
Codes	Unprepared	Afraid or concerned	Lost voice in medical care	Family responsibilities	Learning how to help the preemie
	General medical care	Feelings of disbelief or overwhelmed	Unprofessional behavior	Return to work/school	Looking for reassurance
	Sick and unwell	Feeling isolated/alone	Nursing interference	Lack of space in hospital rooms	Seek out help and assistance
	Transition to home	Feeling guilty	Inconsistent medical care	Visitor restrictions due to COVID-19	Being patient and positive
	Baby's medical care	Stressed/stressful/ Frustrated	Lacking information from doctors	Missed opportunities	Finding ways to feel better/ normalization activities
	Support from loved ones	Proud moments	Cultural and race differences affecting care or relationships	Distance from hospital	Becoming comfortable in medical environment
		Faith, prayer	Lack of trust		Developing relationships with others
					Suggestions for improvement
					Consistent medical staff
					Inclusion in baby's care
					Supportive environment
					Nursing mentor
					Hospital resources
					Information from doctors

The categories and codes were then placed together to identify themes and subthemes. There were five overall themes and two subthemes within the interviews that became evident during the data analysis process. The findings highlight the experience of mothers of premature infants in a Level IV NICU as well as mothering in the Level IV NICU. The themes and subthemes that surfaced during the data analysis are *unanticipated journey to becoming a mother, emotional rollercoaster, mother's lost voice, cultural influences, roadblocks to mothering, unexpected layer to mothering occupations,* and *support from mothering occupations.* Themes and subthemes are organized in Table 4.

Table 4

Themes and Subthemes

Themes and *Subthemes*				
Unanticipated journey to becoming a mother	Emotional rollercoaster	Mother's lost voice *Cultural influences*	Roadblocks to mothering	Unexpected layer to mothering occupations *Support for mothering occupations*

Unanticipated Journey to Becoming a Mother. This theme was prevalent throughout each participant's recount of becoming a mother. Each participant was able to describe her journey of not only becoming pregnant but also of the delivery experience. The participants discussed the deviation from the typical pregnancy and delivery journey that was anticipated when they learned they were pregnant. Consequently, as women envision pregnancy, delivery, and bonding experiences with their newborn infants, rarely are the masses of medical professionals, distressing medical procedures, and tense environment of the NICU taken into

consideration. From the beginning of their pregnancies, many of the participants were under the care of a high-risk specialist, which led to additional, unexpected medical appointments. The participants were also able to discuss in detail the medical attention not only they received but also their premature infant. Hospitalized premature infants experience a great deal of stress in the early stages of life due to repetitive experiences of pain, invasive procedures, loud noise and bright lights, and tactile stimuli that are required for their survival. Therefore, the participants may not have envisioned these factors as part of their journey to becoming a mother as well as caring for their infant in a medical setting. Many of the participants recounted their medical needs, which often highlighted how this deviated from the pregnancy plan in their minds. This deviation was evident in the following exemplar quote from Amy.

> Amy: So, I felt sick for most of my pregnancy between nausea and fatigue. And just my high blood pressure was really the main issue of my pregnancy. And I ended being high risk for it, and I went to the doctor like every week, sometimes twice a week. And so, around 24 weeks is when my blood pressure really got high. Like it was reaching stroke levels. And by the time I reached the hospital, my blood pressure was like 173 over 100 and something. And it was just outrageous. And I thought I was gonna have to have an emergency C-section that night. So, they were constantly monitoring me. But the high-risk specialist, she told me that she really didn't feel comfortable leaving him in for much longer because it could eventually lead to a stillbirth.

The participants also recounted how unprepared they were for the birth of their baby since they were all born prematurely. The participants discussed their imagined birth plan and how premature birth was not considered in their journey to becoming a mother. Unexpectantly, the participants were hurled into motherhood due to their own high-risk medical needs or the medical needs of their unborn child. This new path on their journey to becoming a mother disrupted their imagined experience of delivering their infants within the typical full-term timeframe. Many discussed how they never considered the probability of having a premature infant. Once they were informed by the medical staff about delivering their baby early, the

reality of it seemed far-fetched. This reality was evident in Marsha's exemplar quote in realizing how premature her baby was.

> Marsha: And have the cesarean and take the baby! Oh, boy. Here we go. I've never been in this situation before. This is all new to me. Micro preemie baby. I've never heard that before. Abnormal, premature babies, they come early, but a micro preemie baby, which is around, what, 1 *** pound or anything smaller?

Amy also echoed the same feeling when she was advised by the medical team that she would be delivering her baby early as well. The following exemplar quote from Amy shows her being unprepared for a premature baby.

> Amy: Course, I was caught off guard and so unprepared for everything, but I didn't even know what was considered a preemie, like the earliest birth is like, just everything was new to me.

Once the baby was born, each participant discussed their experience with the medical attention their baby required directly following birth. Many described the anticipation of finding out if their baby was going to survive the birth process. None of the participants expected this to be part of their journey to becoming a mother. The participants did not get to experience the excitement that is centered on the arrival of the infant following a typical delivery. Contrarily, they experienced the fear of whether or not the infant would actually survive the premature delivery. This anxiety-driven experience of fear for survival is often not envisioned as part of the pregnancy and delivery plan, which was evident in Michelle's exemplar quote.

> Michelle: And my daughter was born still less than one pound at the time. I can't remember exactly where she was. Maybe 380. I think that's where she was, 380 grams. I think they were preparing for the worse, which is she wouldn't make any sounds, she wouldn't make any movements. But my daughter actually came out kicking and screaming, which was really funny. And she's still kicking and screaming to this day.

Participants also showed their need to participate in normal activities, finding ways to feel better, and reduce stress while in the NICU. Their unexpected journey to becoming a mother prematurely resulted in the participants reporting that they missed out on having baby showers,

having a maternity photo shoot, shopping for baby clothes, and decorating a nursery at home. These occupations are often fantasized about when a woman becomes pregnant with the anticipation of creating memories of the milestones along the journey to becoming a mother. Michelle was able to sum this up in the following exemplar quote.

> Michelle: When she was in the crib, I had her own mobile. But they put her back in the incubator about a week ago. So, I took it home. But I have her clothes here, and there's little signs. And we were actually making signs for a while. So now, I think just coming every day. And we try to stay as long as possible. And then we've been, I've also started scrapbooking. So, I have made memories of all of these things. And I'm gonna make her as I am making her scrapbook so she knows, she can see. We come, we saw you every day, every day, like you know. But what I am doing for myself, I've already bought her a little tutu with the headband. As soon as she comes home, I'm getting my maternity shoot. She's just gonna be on the outside. I'm giving myself that.

Another unexpected journey to becoming a mother to a premature infant involved medical services that would continue once the baby was ready for discharge home from the NICU, which was not something many of the participants were considering as part of their journey to becoming a mother. The participants were hurled into motherhood early with the need to learn adaptations to mothering occupations for their premature infants based on their medical needs. The participants often spoke about how they envisioned how they would care for their infants at home, which never included the need for special medical care and services. This new path along the journey to becoming a mother ensured the premature infants receive medical care once home was often spoken of in a matter-of-fact way by the participants. Rebecca was able to articulate in the following exemplar quote the needs of her baby once he was able to go home.

> Rebecca: They're just going to see, which ones are available more. They said, look, they'll send, because of the COVID and stuff, they're going to send nurses out. I could go to appointments, but they're sending nurses out. It's easier and safer. So, they're going to figure out that once surgery's over with and recovery. They told me about 2 weeks. On an average, child's doing good. No complications. So, pray for that, and then go home and do therapy.

Although the journey to becoming a mother differed slightly between each of the participants, many common themes emerged during their stories of their lived experience. The most evident was the unexpected turn from the envisioned pregnancy and delivery path and onto the amount of medical care that not only the participants received but also their premature infants. Each participant recounted how becoming a mother to a premature infant may have been unexpected but was well worth the uncharted journey.

Emotional Rollercoaster. The second theme that emerged throughout each interview was *emotional rollercoaster.* The participants told stories, which were enveloped with a variety of emotions from happiness to sadness. The participants not only spoke with emotions during the interviews but displayed these emotions as well. Hence, the participants frequently spoke about being afraid and being concerned for their premature infants with tears in their eyes. These feelings were evident in Rebecca's exemplar quote.

> Rebecca: I was confused and shocked because I didn't even have time to process anything that was going on. I was just very upset. I think I'll always be a little nervous and have that fear because you never know with especially premature babies, you never know what they're going to do. I think every day I'm on my toes, but every time there's a good day, it relaxes me more. And every time I call and get an update, like I feel, I just feel a lot better. But I'll always be a little nervous, especially even when we go home, I'm gonna be nervous because of all he's been through. It's just basically my concerns and stuff and what I've been through. I knew that he was going to have to have some setbacks because you can't really trust premature babies. They'll always switch it up on you. But from him being 3 months and hitting his third surgery Monday, you just you never know what's going to happen. And my concerns are like, how is this going to affect his future and stuff like that?

Many participants also spoke about feeling guilty about having a premature baby. They blamed themselves for not being able to carry the baby full term. Many felt they could have done something different to prevent the premature birth or to prevent the baby's need for surgery. Rebecca spoke about this in the following exemplar quote.

> Rebecca: I blamed myself. I feel like I could have done something. I feel like it was my fault. My supply wouldn't come in and lactation told me they even came in there was trying to help me out. And they're like they asked me what happened, like birth is birth. And something like that caused the delay in some moms. It can affect and they inform me it wasn't my fault or anything. Don't feel bad. It just happens. But I felt bad because I didn't want him on formula at the time because of what happened with him. And it was just a little dangerous for him. So, I felt like I couldn't do anything to help him. And I just, I was gone, I was going crazy with it. Just that it's, it's hard, it's hard seeing him with wires and tubes on him and stuff. It's not it's not easy, but we all know that. But I just wish I think all moms and dads wish that they could just take their place or just make it better. And it's really frustrating just having to sit back and not be able to fix it or change anything. But all I do is should basically pray and just try to get through it.

While many of the participants had large support systems and significant others to lean on in time of need, some participants either did not have a lot of support or began to feel isolated and alone. Feelings of isolation and feelings of being alone in the NICU affected an overall sense of wellbeing for some of the participants. In the following exemplar quote, Amy discussed her feelings.

> Amy: I just feel very isolated and lonely. You know. And I was telling my mom that I was like even those people around me, I just feel so alone. And then my son's father, who I haven't even heard from in so long as he visited, but I honestly didn't want him there because it's just it wasn't consistent, you know.

Although there were emotions that elicited crying and sadness during the interviews, the participants also portrayed happiness and proud moments when discussing their experience of having a premature infant. From being happy about the small improvements their baby was making to being amazed by their exuberance, each participant had something to be proud about when discussing their experience. Marsha's exemplar quote sums up how proud she was of her son.

> Marsha: And when I get those good news, I'm like "Yay," I am cheering him on, I'm one of your biggest cheerleader.

Being astonished at their premature infant was also evident during the interviews. Amy was able to exclaim in the following exemplar quote how surprised she was of her premature son when she first saw him in the NICU.

> Amy: And I was just so amazed at my son, like, even though he was so tiny and fragile. It was just amazing to see him here. I mean, he was moving around, he's very active since he was in the womb. And just to actually see him out and being just as active as he was in the womb, which is a lot to take in.

Having faith and praying was discussed by the participants as affecting their stay in the NICU. Many voiced how needing to have faith that their baby was in the right place to get the care they needed to survive was important, which was evident by Kristina's exemplar quote.

> Kristina: I know I had a lot of time and again, continue to pray and keep your faith. I mean, I can't stress that enough. Even though our journey seems like it's almost over, it still seems so far away.

The participants were very candid in their interviews when speaking about the range of emotions they experienced during the hospitalization of their premature infant. Many joyful moments were conveyed when notable milestones were met; however, stress and concern were often discussed by the participants. Moreover, participants alluded to the fact that the feelings of stress were a direct result of their opinions and concerns not being taken seriously by the medical staff, which led to the development of the third theme, *mother's lost voice.*

Mother's Lost Voice. The third theme to emerge in the data analysis process was mother's lost voice. Participants reported they felt as though they were not being heard during their prenatal care. Another concern was their lack of being heard when bringing up issues with the care that their infant was receiving in the NICU, which was evident in the following exemplar quote from Michelle.

> Michelle: In the beginning, I had some issues with my OBGYN. I was noticing things that I just felt weren't normal. I had addressed these things with my OBGYN at the time actually went through three OBGYNs. The first one, which is a distance issue. The

> second one is the one I had a lot of just she wasn't hearing me issues. So, one of the things I brought to the attention of my OBGYN was that for someone who is not working, I am extremely tired, extremely tired. I also mentioned to her that I wasn't having any cravings. Nothing was bothering me. I felt normal. And the only thing that I was craving was cold drinks, ice, and we would later come to find out. Let me backtrack. I ended up going to her as well, saying, comparing myself to the other young lady, saying, how come I'm not showing? Should I be putting more protein? Can I eat, drink protein drinks, or something like ensure or something? She kept telling me no, dismissing it off as well you're just a small woman. I knew, especially because I felt like I advocated so hard for myself and for her. And I knew something was wrong. And I left. *** In regard to her baby, and one of the ways I felt about it was, you're trying to put accountability on me. And as her parent, I've asked not one, not two, not three, four times. I've done my job. I'm advocating. I kept saying it didn't look right. It didn't feel right. I did what I supposed to do. Don't put that. Well, who did you speak to? I'm not a secretary. I thought that very, you know, that's not my job. And I kept that inside too. I just said. Well, I don't know. But it should be documented. I'm upset because this is my fourth time. And I think people took that as it's your fault. No, let me tell you this, I'm not that type of woman. It's not my fault. I know I'm doing the right thing. Where I feel disheartened is, you know, there is this. It's fact. It's fact that Black women don't get heard in the medical industry. This is a fact. And I think I have shared with you my OBGYN experiences, which led us to be here. And I advocated for myself then, I'm damn sure gonna do it for my child now. But four times, it is always gonna be a constant struggle.

One of the issues that became evident with not feeling like the mothers were being heard was inconsistent medical care. Many of the participants were seen by a different doctor at every prenatal visit. Many of the participants showed how they attempted to speak up in medical appointments but were often dismissed. One participant even alluded to the possibility that her concerns not being taken seriously led her to being admitted to the hospital in preterm labor. Crystal's experience with inconsistent care was evident in the following exemplar quote.

> Crystal: One, I was going to a high-risk doctor. I never seen a doctor until my last appointment and that was because I questioned why when I come to the doctor, I don't see a doctor I only see an ultrasound tech. And when I was at that appointment, the ultrasound tech had told the doctor or something about the ultrasound and that she wanted to do a vaginal ultrasound and she stated, "well, we could just wait till the next visit." Then I start saying something. I guess the ultrasound tech saw something, but the doctor didn't do anything. Then a week later, I started bleeding and went into labor.

Another situation with inconsistent medical care was different nurses caring for their infants in the NICU. The participants often discussed how their voices were not heard when the medical care was not consistent. The participants often spoke about how nurses often performed caregiving tasks differently and often avoided changing their practice, despite the mother's expectations or voiced concerns. This breakdown in care practices often frustrated the participants and left them feeling as though the care of their infant was subpar and their opinions of caregiving were overlooked. On occasion, nurses were rotated into the NICU from other units in the hospital, which participants stated was of concern for the participants. Erica stated this concern in the following exemplar quote.

> Erica: Well, I notice recently I'm not too sure like how the scheduling is, but I know, for instance, like they've been getting a lot of PICU nurses that don't really work on the NICU side. So, they'll come and they're not familiar with, like the bedtime routine with the bath and things of that nature, because they state that on that side, they don't bathe the babies, or they don't bathe the children at all in the evening.

Data analysis showed that participants were often left in the dark about the situation that was going on with their baby. The participants stated on many occasions the need for more information from the medical staff; however, despite the questions being asked, the participants left medical appointments without being heard. Furthermore, lacking information from doctors with both prenatal care and the infant's care was evident during the interviews. Many of the participants were unknowledgeable about the reasons for being transferred to the Level IV NICU from their birth hospital even when they were requesting information from doctors about the need for transfer, which was evident in Marsha's account of being uninformed by the doctors, despite asking questions in the following exemplar quote.

> Marsha: And she was like, oh, "I want you to go straight to the hospital when I let you go." I'm like, "What?" Because this is new to me. I don't know what's going on. And I had no idea what duodenal atresia was. That's when I started Googling it. What is this?

> Explain this to me. What do you mean? How does a baby not be able to eat? How is this or what is that?

During data analysis, the participants expressed their inability to participant in mothering occupations directly following the birth of their premature infant due to the required medical attention of their infant. The participants stated they missed opportunities to mother following the delivery of the premature infant, which was expressed by the participants as a lack of opportunities to bond with their infant due to the medical needs of not only themselves but also of their premature infants. Additionally, the participants were unsure which questions to ask in regard to mothering in the medical setting, which was often rooted by their experience of not being heard thus far in their medical care, which was evident by Amy's account in the following exemplar quote of missing the opportunity to bond with her baby directly following birth.

> Amy: So, I didn't see him until the NICU people had gotten him situated. And they wheeled him around up there a little bit. And I looked up because I could barely see him, but because he was in, you know, the little what is it, the incubator. He was in that. I did not see him until, what was it, the following day, I want to say, because, like the same day I was on magnesium and so with that I couldn't move or anything like that, I had the catheter in still and all of that. So I was, it was like I missed the whole day of seeing my child. I felt so sad like I was. And it was also discouraging, like, am I ever gonna be able to hold him and make some type of connection other than, you know, looking down on him and talking to him, you know, wearing the cloth and bringing it back and switching it out? It kind of made me sad because I'm just like, at what point am I going to really be able to develop a relationship with my son, you know? And when you're new to this, it's just like you don't know what questions to ask or any of that.

Overall, the participants were able to discuss their experience of being a mother to a premature infant in the NICU, which led to them feeling as though their voices were not being heard not only during their own medical care but also their infant's care. A factor to their voices not being heard could be due to cultural differences, which became an unexpected theme during the interviews. Cultural differences between the participants and the majority of medical staff appeared to lead to a breakdown in communication, which affected the participants' perception

of mothering their premature infant. The breakdown in communication often left the participants feeling as though their voice was not heard nor was their opinion valued in the care of their premature infant. Another aspect of cultural differences of the participants was the varying of educational levels, which may have affected their ability to effectively communicate and understand the information being given to them. Moreover, the participants' past experiences in the medical community may have affected their trust and confidence in the care of their premature infant in the NICU. This impact to their lost voice led to the development of the subtheme: *cultural influences*.

The subtheme, *cultural influences*, was evident throughout the data analysis of the interviews with the participants. In the Level IV NICU, 75% of the nursing staff is White and 90% of therapy staff is White. There were six participants, 75% who were Black. When asked about the culture of the NICU, one participant was able to discuss a time when she felt the medical staff was being racist. Michelle's exemplar quote highlights how she felt when engaging in conversation with a respiratory therapist and a nurse in the NICU.

> Michelle: I had two nurses, one respiratory, one regular nurse say they found out that I was a flight attendant. And they asked me, do I have any issues with people trying to sneak in? And I said, no, no. Actually, my response to be funny was, oh, you mean from Europe. Right. Because I knew what they meant. And she's like, "No, no, you know. You know what I mean?" And they took it and went back to the immigration thing and literally said, "Yeah, because they sneak in and then they get upset when their kids end up in cages." And I, and that, I think would qualify as a racist moment. And I kind of just was floored because I was like, that's a terrible thing to say, you know?

Another participant discussed the conversation she had with the neonatologist at the birth hospital before the premature birth of her baby, which took on a racial connotation. In the following exemplar quote, Kristina shares her experience.

> Kristina: That night about an hour or 2, a doctor came in and he looked really scary. And I was like "Hey?" And he said, "How are you doing Mrs. Kristina?" And I said, "I'm fine." He's like, "I am a neonatologist down in the NICU," you know, I was like, "What

> are you doing here?" You know? And he said, "Well, I'm here to discuss, you know, the NICU and tell you how things go when the babies are born early. Looks like your baby is 25 and 1. I'm going to give you some paperwork that shows you the statistics." And he said, "One of your advantages is," and I hope that this is what I can say, he said, "One of the advantages that you have is that you have an African-American girl." He said that "Most African-American female babies, they fight a little bit harder. They're a tad bit tougher. They're heart is stronger." And I said, "Well," I told him, I said, "I don't know if it has anything to do with race." I said, "But Momma has a really strong heart." I was like, "So if I can bring her out and be anything like me, she's gonna fight to the day that she doesn't have to fight anymore."

Another way difference with culture became evident occurred when participants were receiving information from medical staff. Many of the participants felt as though they did not understand some of the language that was being used in the NICU. The culture of the NICU is embedded in the use of medical jargon by the medical staff. Consequently, the hospital environment is also defined by the highly technical medical equipment that is being used for life-saving measures. Many of the participants stated they heard words that they never knew existed, which caused them not only confusion but the need to write these words down to look up later, which affected how they felt included in care and knowledgeable about the care that was happening with their infant. Crystal stated in the following exemplar quote how language was an issue, which was causing her to feel frustrated.

> Crystal: Just maybe as far as language, I couldn't understand some of it for his care. Because at first, I was losing patience, like when they had to give him the paralytic, I wasn't understanding why, I thought it was a bad thing. But it actually was a good thing because they were putting his body to rest and letting the ventilator work for him. And as I said, it just worked and with a better outcome and it helped him, for them to do that to him.

Due to the cultural differences and mothers not feeling heard, a lack of trust was evident when participants were discussing their experience of having a premature infant in the NICU. Michelle was able to discuss how she felt in the following exemplar quote.

> Michelle: I feel like what I said last week was I feel like there's a good communication between me and the doctors. Well now I. And it's not just this isolated event. It goes back

> to I made a complaint about the nurse. I was told she wouldn't be in there. But if she could be the next-door neighbor nurse and if my nurse went to lunch, you know, she would. OK. What I what I feel more now, too, is more exhausted. You know, I have a lot I have a lot on my plate. You know, my job is unstable in the airline. It's COVID times. I have a child in the NICU now. She's in your care 24 hours. And I'm only here 8 hours of the day. You know, if that. And now you've made it to where I feel like I need to be here 24 hours because you didn't respect my voice, which was I don't want this nurse here. They didn't respect what I was saying when I kept saying there's something wrong with the wrist and it kept being dismissed by each person. So now I don't feel less empowered. I feel like I can't trust people here. And that is a that is a disheartening feeling.

The participants openly shared their insights about how the NICU culture and the culture of the staff not only differed from themselves but affected their ability to mother their premature infant. These differences left them feeling unsupported, unheard, and in uncharted territory. The cultural differences appeared to serve as a barrier to mothering, which led to the fourth theme of *roadblocks to mothering.*

Roadblocks to Mothering. The fourth theme that emerged was how many *roadblocks to mothering* the participants experienced. Participants often spoke about the barriers and hinderances to mothering in the NICU. Whether it was due to the distance from the hospital, family responsibilities, return to work, visitation restrictions due to COVID-19, lack of space by the bedspace, or unprofessional behavior of staff, the participants stated these barriers affected their ability to mother. Many of the participants lived far away from the hospital, which affected their presence in the NICU but also the inability to live at home due to the length of hospitalization. The hospital was able to offer sleeping arrangements for mothers who lived far away. Emily was able to state how the distance affected her and her family in the following exemplar quote.

> Emily: Well, of course, number one, you won't ever sleep as good as what you do in your own bed. But the sleep rooms are very much appreciated just because I can be down the hall from *** my baby and just be close to her and know that if she needs me during the night, also, I stay in here very late at night, so I'm able to hold her longer and be with her longer and not have to go far. Not have to drive somewhere. Drive the time to get home.

> So, it gives me more time with her. And also, when we switch out, my husband, switch out for COVID. You know, when she was here for surgery, we were able to stay. They have double sleep rooms. So, we were actually able to both be here for. Which was nice, too. But, yeah, the sleep rooms have been greatly appreciated. The shower. The only downfall is because there are nine sleep rooms and some of them are doubles. But, you know, taking turns to shower, which some people shower at night and some in the morning, you just gotta kind of figure out your timing with the other parents.

While the sleep room was available and helpful for Emily, it was not an option for other participants who did not have support at home to help care for the household, pets, or other children. Rebecca was able to state in the following exemplar quote the struggle of living far away from the hospital.

> Rebecca: I try to come every day, maybe once or twice a week. I have to do my errands and stuff. I can't always make it, but usually I try to make it every day, at least for a couple hours in the morning. It is it is a good drive. And you're having to fill up a car like just about every day, every other day just to come to *** the hospital. Yeah, but it's worth it.

Returning to work looked different for some of the participants. All the participants who returned to work either went back to the work environment or were able to work from home. Marsha discussed in the following exemplar quote how going back to work was difficult.

> Marsha: It's kind of a lot more to me is a lot more difficult, not just because of going back to work, but also because of that virus that's going around. So, in my mind, I work around a lot of people. I work for UPS. I'm a supervisor at UPS. I haven't had a bad day until yesterday when I went back to work because now you have to focus on what's going on at work. You have all this other stuff going on. Like, I don't think I'm ready for this because I was at the point last night was like I think I'm just gonna go ahead and take additional leave because I'm not ready.

A barrier to mothering for another participant was how to mother while also working when she was allowed to work from home. In the following exemplar quote, Erica was able to discuss how returning to work was for her.

> Erica: Well, being that I am working from home. It's a lot of holding her while working on the computer and then trying to play with her on the floor. It's a lot of juggling. So, I guess I'm just managing because I have to. Well, initially we were working from home

> due to COVID. Now we are transitioning back into the office. But they are letting me stay home due to her being in a NICU.

The hospital instituted a new visitation policy due to COVID-19. This visitation policy created a limited number of caregivers to be able to visit the hospital. The new visitation policy only allowed one caregiver to be present at the bedside at one time. A second caregiver could be at the bedside every 24 hours, which allowed caregivers to take turns at the bedside. The impact of this new visitation policy was evident in the following exemplar quote from Erica.

> Erica: So, we were both able to be at the bedside until they changed it. So, I guess it's we both can't visit at the same time. And I guess our grandparents would have come to visit, but due to COVID, yeah. I would say just COVID overall stops a lot.

While in the NICU, the space at the bedside often prevented the participants from engaging in mothering occupations. The three areas of the NICU had different bedspace configurations in which some bedspaces had more room than others. Amy was able to voice her opinion about the hospital bedspaces in the following exemplar quote.

> Amy: Really small. It's just like, I don't know. Seems like it's never enough space, especially when it is time to do kangaroo care. It's like I try to let the chair all the way back and it just hit the wall.

Another roadblock to mothering that was evident in the interviews was unprofessional behavior of the medical staff, which often interfered with the participants feeling comfortable about mothering in the NICU. Whether it was a nurse overstepping their professional boundary or the inappropriate use of language while caring for the participant's infant, the participants stated this unprofessional behavior made them feel unwelcomed and uneasy. In the following exemplar quote, Michelle was able to state her experience of unprofessional behavior.

> Michelle: I think, etiquette, like I think sometimes, and I can say I see it a lot, too, in my industry, people forget where they are. People become, what's the word, desensitized. That's a great word. Desensitized to what they're doing in their environment. And I think they become very comfortable. But just like I think people need an etiquette class on how to do things and how to how to handle things. I just kept quiet on it. And that's sad to say,

> I just kind of lived and kept quiet after that. When do you say you're not going to argue like, OK?

Nursing interference became evident as a roadblock to mothering during the interviews as the participants were discussing their experience of mothering in the NICU. Nursing interference was described by the participants as overstepping their boundaries, assuming so-called ownership of the infants, and inserting inappropriate opinions of the mothers, which led the mothers to feel blame and guilt. Learning to mother in the NICU was difficult, but navigating the nurses was an unforeseen situation, which was evident in the following exemplar quote from Rebecca.

> Rebecca: And I've never went through that before because everybody has been amazing here. And it caught me off guard. I'm not going to lie, it like caught me off guard. People can judge you whether it's other parents or maybe a nurse. But that I, I talked to another nurse that, you know, really helped me. And I told her about it, and I called up there and they were talking to me, and they're gonna talk to management about it. And I haven't seen her since. But she did walk in my room after I got her off my son's nursing list like his list. She did walk in here and kind of like bombarded me with questions. And I'm like, you know, that's a little out of place, you know, with my baby. I'm spending time with my son. But that was the only issue I ever had. But she has not bothered me since. I haven't even seen her over in this area. And I think you guy's management knows about it. So, I don't know what happened from there, but it was addressed to the big bosses and stuff. And it's just that one nurse basically kind of being a little possessive over him. You need to back up a little bit. And I addressed it as soon as it happened as soon as the rude comment came out. I addressed it, and I got that figured out. No one ever like oversteps or tells me I'm a bad mom. But that's how I felt when that nurse made those comments. Like, I've already beat myself off over this because I can't take him home. I can't change anything that I did. And that really hit me hard. And it took me a while to get over it.

There were many roadblocks to mothering as told by the participants during their interviews. The barriers were due to the social situations of the mothers, the NICU environment, the medical staff, and the medical fragility of the premature infants. Additionally, the length of hospitalization also added an additional barrier to mothering occupations. As the participants discussed the difficulties with mothering occupations in the NICU, the fifth theme emerged, which was *unexpected layer to mothering occupations.*

Unexpected Layer to Mothering Occupations. This fifth theme became prominent throughout every participants' account of their experience of being a mother to a premature infant and performing mothering occupations in the NICU. When a mother envisions herself caring for her baby, the foundational layer of mothering occupations and co-occupations are thought of, such as bathing, feeding, and dressing the baby. These building block layers to mothering occupations are often in the setting of the home environment with close family members present for ongoing support and advice. Layers to mothering occupations in the NICU that were unforeseen included the fundamental knowledge of the meaning of being a premature infant in the NICU and how premature infants require adaptations to mothering occupations for optimal neurodevelopmental outcomes. An additional unanticipated layer to mothering occupations in the NICU was the support from online social media in the context of a worldwide pandemic, which was sought out to improve the overall sense of wellbeing of the mothers while at the bedside. The participants also showed the amount of support they received from medical staff for performing mothering occupations in the medically driven environment. These layers to mothering occupations, such as navigating medical equipment and devices in the NICU environment were unanticipated in the care for their premature infant. Furthermore, learning how to help their premature infant became a topic that each participant highlighted in their story. Learning how to help the premature infant was apparent in the following exemplar quote from Amy.

> Amy: I mean, the therapists that I've met have been helpful and teach me ways to comfort him when his nurses are doing like hands-on care. So, I would say it's a positive experience. So, kind of like, I guess, doing the hand on the head and hand on the feet to kind of. What is it? To remind him of being in the womb and helping them to calm down? Because from what I've been told by his nurses and therapists is that he doesn't really like being touched. It's kind of like overstimulation for him. So, to be able to do that and talk to him while I do it is really good.

Another unexpected layer to mothering in the NICU was becoming comfortable in the medical environment. All of the participants discussed how the medical environment was intimidating in the beginning, but over time, they became comfortable with the support and guidance from the medical staff. In the following exemplar quote, Rebecca was able to articulate how the medical equipment was daunting.

> Rebecca: At first, I was like, I don't even want to touch him, or I'm gonna break him or do something wrong. But now it's like, oh, I know where that goes. I know where this goes. Like, it's normal. That's OK. I feel more comfortable. And if one of his leads are off, I know how to where to put it back on. It's a lot better now. At first, I was like, what do I do?

Looking for reassurance was an unexpected layer to mothering in the NICU. With the lack of support groups in the Level IV NICU due to COVID-19, the participants were often left to seek out their own support from outside the hospital. Often the participants were alone at the bedside due to the visitor restrictions of the hospital's COVID-19 policies, which limited bedside support from their significant others and family members. Therefore, the participants were often seeking out information and support when they needed from the medical staff. But also, when they didn't understand information or needed confirmation that things were not as bad as they were feeling, they often sought out other's stories similar to their own from social media. In the following exemplar quote, Rebecca was able to report how she helped herself to feel better.

> Rebecca: On social media was just a group of moms. I was just doing some research and it just they have some similar stories and stuff. And they talked about a lot. And I didn't, I never commented on it, but I like to read it and it just makes me feel better and it gives me better hope and it makes me more relaxed.

There were suggestions for improvement for the NICU by each of the participants. The suggestions for improvement were used to highlight the ability of the mothers to advocate not only for themselves but for future mothers in the NICU. This advocacy was an unanticipated layer to mothering in the NICU as all participants were able to identify areas of need to improve

the experience of having a premature infant. As the length of hospitalizations in the NICU increases for the care of medically complex premature infants, the need for support of mothering occupations also increases. The unexpected layers to mothering occupations identified by the participants has led to suggestions for improvement and identified barriers to performing mothering occupations. The suggestions for improvement from the participants ranged from environmental needs to bedside services. Notable was the impact that COVID-19 had on visitation and the suggestion to have webcams at the bedspace. Emily was able to discuss these suggestions for improvement in the following exemplar quote.

> Emily: I've already suggested this before, was the live cameras from 9:30 in the morning till 11:30 a.m. and then 9:30 p.m. to 11:00 p.m. because of COVID, especially. But to keep germs down, too. They have the cameras on the babies so you can just watch your baby. You know, it wasn't sound, but you could just watch your baby. So, like grandparents or people that live out of town that couldn't, you can give them that code and go on and watch your baby. That was my biggest suggestion for here, because it's just a comfort for when you can't be there or when family can't be here to meet or see her. Then, it's just a comfort. There are only two lactation rooms. I don't mind pumping by bedside, but I think that once you have employees using the lactation rooms and also the mothers using the lactation room, I've had to come back several times with those to say, yeah, I just think that if there was any way of getting more of those, it would be nicer. There's not, there's just not enough bathrooms, I think, at this facility.

A subtheme that evolved from the theme unexpected layer to mothering occupations was *support for mothering occupations*. When a mother envisions the birth of her infant, the need for medical attention and ongoing support from medical staff is not often in the picture. Moreover, the need for support from the NICU staff for performing mothering occupations at the bedside is an unanticipated aspect of becoming a mother. However, the medically fragile premature infant often has special care needs to ensure not only survival but improved long-term developmental outcomes. The participants voiced their experience with having support from the NICU staff when asked about their ability to perform mothering occupations. Being mentored by the nursing

staff about how to safely perform mothering occupations was prominent in the stories from the participants, which was evident in the following exemplar quote from Emily.

> Emily: The nurses are worried about you doing as much hands on as you want, changing the diapers, giving the baths, changing her clothes, taking her temperature. Just anything that you want to do, they'll allow you to do. Each nurse, you learn from each nurse and you learn something new from each nurse because they all do it just a little bit differently. So just how handling her with the respiratory things and then, showing how to change lines for her g-tube and her feedings.

Another account from Amy about how mentoring from the nurse allowed her to hold her baby for the first time. Amy's exemplar quote stated how appreciative she was of the nursing staff.

> Amy: It was a nurse. And I'm not sure she's still here. I hope she is. But she was like, would you like to hold him? Have you ever held him before? And I was like, no, she's like OK. Well, we can make it happen. I just have to clear it was the doctors first and make sure everything's fine. She's been teaching me how to talk to him when I'm holding him as well as when I'm just standing at his bedside with my hands in the isolette. So, they've been the most helpful to me.

Being included in all aspects of bedside care also improved the mother's ability to perform mothering occupations. Every participant discussed how being included during the nurse's care times improved their comfort level of being a mother in the NICU, which is evident in the following exemplar quote from Amy.

> Amy: His nurse asked if I wanted to help her with hands-on care. And I was like, "Sure." Of course, I was scared. But I checked his temperature and I changed his diaper. And it was here where I was able to do the suction of the spit bubbles and stuff like that. And yeah, this just little things that kind of helped me feel like I'm helping to take care of him.

Every participant discussed how the help and assistance from the medical staff assisted them in mothering in the NICU, which was an unanticipated layer to mothering. The participants often discussed how being and becoming a mother in the NICU was uncharted territory and required an all-hands-on deck mentality to care for the premature infant. Not only did participants identify the need for assistance and support for mothering a premature infant in the NICU but also of the need to take breaks from the high stress environment. Participants discussed how nursing staff

made them feel as though it was okay to take a break and even to support their decision to do self-care tasks away from the hospital, especially with prolonged hospitalizations. Amy was able to state the need for assistance and wellness in the following exemplar quote.

> Amy: A piece of advice would be to ask for help. You're not expected to know everything or do everything by yourself. So, if people offer their services, take it. I mean, it's a lot to come into. Honestly, no words can ever prepare you for your role as a NICU mom. So definitely, take the help and also know that it's OK to not be up here every day. That's something I had to learn because when he first got in the NICU, I felt like I had to be there every single day and that quickly, not necessarily it got old, but it started to take a toll on my mental health as well as my physical health. It became difficult to recover from giving birth. So just, it's OK to take a break.

Consistency had a significant role in the medical care of each participants' premature infant. The participants discussed how having a primary nurse assigned to their infant improved the care they received and having the same doctors also benefited their infant. This highlighted the importance of having support from NICU staff. Michelle discussed the importance of support from NICU staff in the following exemplar quote.

> Michelle: It's nice because you know, their flow of things, you know. You know what they're comfortable with, seeing a familiar face. I think it benefits my daughter. You know, one less person she doesn't know touching her. She loves her primary nurse. There are a few nurses she really warms up to here, but she loves her primary nurse. You know, our primary nurse has her and I know that she takes care of her and I know how she works. I know she's attentive. You know, it's nice.

The participants discussed how the cultural environment of the NICU, which consisted of the nurses, neonatal therapists, and ancillary NICU staff, supported mothering occupations. They also discussed the importance the physical environment had on their ability to mother in a medically advanced environment. The physical environment of the private room configuration was discussed as having supportive properties to the participant' ability to perform mothering occupations in the NICU. One benefit of being moved to a private room on the discharge unit of

the Level IV NICU is that one has more privacy. Crystal was able to indicate the how the physical environment supported her in the following exemplar quote.

> Crystal: It's much quieter and makes you feel more at home than being in open spaces, more noisy, because you hear the baby's monitors and stuff going on so. I am getting to have more bonding time in the private room.

The service environment (AOTA, 2020) of the Level IV NICU and pediatric hospital was supporting the mothers in mothering occupations. Per the Occupational Therapy Practice Framework (OTPF), the service environment consists of any type of service that meets the needs of any group of individuals (AOTA, 2020). The services that were provided by the hospital included a free lactation diet in the cafeteria, discounted parking passes, sleep rooms, and access to the Ronald McDonald house. The service environment of the Level IV NICU included ancillary services, such as chaplain, child life specialist, and all of the items the babies need, which supported mothering occupations. Marsha was able to highlight the hospital resources in the following exemplar quote.

> Marsha: I like the fact that everything is provided. I mean, I didn't know that they provided as he's growing now when he's able to wear clothes. I didn't know that all that stuff was provided. The clothing is crazy because I always like, you know, one size fits all the small babies. Oh, they are amazing because they have even micro preemies. There’re all the hats, the little Snuggies that they snuggle him in. I’m like, wow, they have thought about everything in here.

The participants recounted how environmental factors, such as the cultural, physical, and services, supported and hindered mothering occupations in the Level IV NICU. The environmental factors, such as the physical layout of the NICU, the technology involved, support and relationships with the staff, attitudes of the NICU staff, and services and hospital policies, all had a significant role in supporting mothering occupations or acting as a roadblock to mothering occupations. Overall, the themes in this dissertation study have emphasized the lived experience of mothers of premature infants in a Level IV NICU.

Summary

The purpose of Chapter 4 was to present the findings from the in-depth data analysis of interview data. In this hermeneutic, phenomenological study, the investigator utilized two semi-structured interviews to explore the experience of mothers of premature infants in a Level IV NICU and their experience of performing mothering occupations. The data analysis led to five main themes for the dissertation study: *unanticipated journey to becoming a mother, emotional rollercoaster, mother's lost voice, roadblocks to mothering,* and *unexpected layer to mothering occupations.* In this chapter, detailed descriptions of each participants' experience with having a premature infant in the NICU and performing mothering occupations were discussed. The next chapter is a detailed interpretation of the data, recommendations for future research, and limitations of this dissertation study.

Chapter 5: Discussion

Introduction

This hermeneutic phenomenological study included the questions "What is the lived experience of mothers of premature infants in a Level IV NICU?" and "What is the mother's experience of performing mothering occupations in the Level IV NICU?" Mothers of premature infants who had been admitted to the Level IV NICU for at least one month answered the questions through semi-structured, in-depth interviews. A total of eight mothers were individually interviewed on two separate occasions, 2 weeks apart. Data analysis using a hermeneutic phenomenological approach (Cohen et al., 2000) yielded five themes and two subthemes. The themes were framed using the PEO framework, highlighting the interplay of the person, environment, and occupation (Law et al., 1996) as well as the occupational theory of human nature, focusing on doing, being, belonging, and becoming (Wilcock, 1993) to focus on the experience of mothering premature infants in the medically complex environment of a Level IV NICU. In this final chapter, the investigator discusses the findings, implications for practice, future research, and public policy, limitations of the dissertation study, and recommendations for future research.

Discussion and Interpretation of Findings

The narratives that each participant told of their lived experience of being a mother to a premature infant in a Level IV NICU influenced the data analysis. Each participant shared the experience of becoming pregnant, delivering a premature infant, and having a prolonged admission in the NICU. Each participant recounted her stories with great emotions and openness to their lived experience of mothering a premature infant over a prolonged period of time in a medically complex environment. At the conclusion of the data analysis, five main themes

emerged which were *unanticipated journey to becoming a mother, emotional rollercoaster, mother's lost voice, roadblocks to mothering*, and *unexpected layer to mothering occupations*. There was a subtheme for *mother's lost voice* which was *cultural influences* and a subtheme for *unexpected layer to mothering occupations,* which was *support for mothering occupations*. The themes and subthemes are discussed. The first theme was *unanticipated journey to becoming a mother* in which each mother discussed the trials and tribulations to becoming pregnant and delivering her infant prematurely. The second theme was *emotional rollercoaster* in which the mothers recounted the array of emotions, which they experienced with becoming mothers to premature infants in the NICU. The third theme was *mother's lost voice* in which the mothers identified occasions when they were not heard by medical staff during their own medical care as well as the care of their premature infants in the NICU. The fourth theme was *roadblocks to mothering* in which the mothers discussed situations when they had a difficult time mothering their premature infants in the medically complex environment of the Level IV NICU. The fifth theme was *unexpected layer to mothering occupations* when the mothers discussed their experience of learning how to mother with the support of the medical staff in the NICU environment.

Individual Description of the Lived Experience

Participant #1 Marsha. Marsha, a Black mother of six, was the eldest of the participants at 39-years old. She was very open and honest about her experience with becoming pregnant, which was unplanned and resulted in increased medical appointments with specialists. The theme of *unanticipated journey to becoming a mother* was evident in her account of becoming pregnant and delivering a premature infant. Her experience during the prenatal period was of many doctor's appointments when she had inconsistent medical providers. Marsha voiced many

times during the interview her reliance on the Internet for answering medical questions she had once leaving medical appointments, which may have been directly related to having inconsistent medical providers during her prenatal appointments or a result of decreased health literacy. Marsha's experience with mothering in the NICU appeared to be directly related to how her baby was doing from a medical standpoint. She often relied on the nursing staff for the majority of caregiving tasks when her baby was considered critically ill. Furthermore, the medical equipment was intimidating to her and made her feel nervous. Despite not feeling comfortable in participating in the care of her baby due to his medical status, she often spoke of being in the NICU by sitting quietly at his bedside. Being has been described as a time of reflection and when plans are formed for the future (Wilcock & Hocking, 2015). She also spoke of participating in the bedside medical rounds with the NICU staff, which facilitated a sense of belonging. Belonging has been described as a facilitator of feelings of attachment, connection to others, and feelings of fitting in (Wilcock & Hocking, 2015), which appeared to influence Marsha's dedication to visit daily, despite her feelings of nervousness to perform co-occupations with her medically fragile infant. Unfortunately, Marsha was unable to participate in the follow-up interview due to her baby dying unexpectedly, which points to the magnitude of how fragile the premature babies in a Level IV NICU are and how supporting mothers throughout the hospitalization is of upmost importance.

Participant #2 Emily. Emily is a 36-year-old, White mother of four children. Emily's personality was shy and soft spoken. She repeatedly exclaimed how grateful she was for the Level IV NICU. The feeling of gratitude was a result of the birth hospital's opinion and recommendation of transferring medical care to comfort care due to her baby's diagnoses and need for multiple surgeries. Emily stated the Level IV NICU was the only place that would

perform the needed surgeries for her baby's survival. Therefore, she voiced appreciation for the care her baby had received. Emily often expressed how the nursing staff and the occupational therapist facilitated her ability to perform co-occupations with her baby. The concept of doing enables feelings of well-being and improves one's health by participating in preferred occupations (Wilcock & Hocking, 2015). Emily pointed out the hospital resources she utilized allowed her to spend increased amount of time in the NICU. The hospital resources acted as a facilitator to the process of becoming a mother. Becoming has been described as the process of transformation (Wilcock & Hocking, 2015), which is important for a mother of a medically fragile, premature infant. Emily's experience with relying on hospital resources shows the theme *unexpected layer to mothering occupations* as she often spoke of how grateful and surprised she was for the support. However, her experience with mothering during a prolonged admission included feelings of stress of needing to be at the bedside and wanting to be at home with her other children. She leaned on support from her husband and her sister for the care of her other children at home. The support from loved ones allowed her the ability to spend the weekends at home with her other children, which points to the importance of recognizing the social differences between mothers as many of the participants lacked support and resources to be a consistent presence at the bedside.

Participant #3 Rebecca. Rebecca was the youngest of the participants at 19 years of age, White, and a first-time mother. She was unemployed and lived 46 miles from the hospital. Her bedside presence was limited and inconsistent as she visited 1 to 2 days per week. When probed about the reason for the limited presence, she stated the cost of gas and the need to care for her dogs as the barrier. When present, Rebecca spoke of her experience with holding her baby and playing with him. The doing (Wilcock & Hocking, 2015) of these mothering occupations and co-

occupations allowed Rebecca to report satisfaction for caring for her baby. Nursing staff began to have opinions about Rebecca due to her lack of presence, which eventually led to a situation between her and one of the nurses. This conflict appeared to have an influence on her experience of mothering in the NICU and may have affected her visitation to the hospital. Although Rebecca was open about the support that she received from the nursing staff, she also spoke of the interference she perceived from the nursing staff for mothering her baby. The barriers Rebecca experienced for mothering in the NICU were supportive of the theme of *roadblocks to mothering.* Her narrative brings to the forefront the importance of education and training for staff for family-centered developmental care.

Participant #4 Erica. Erica, a 35-year-old, Black, first time mother worked full time and was at the bedside daily. She had the longest admission at the time of the interview as her infant had been admitted to the Level IV NICU for 4 months. Her interviews were most interesting due to the fact that she did not acknowledge the plethora of medical reasons her infant was in the NICU. She mostly discussed prematurity as the reason for admission to the Level IV NICU, despite other medical complications, such as BPD, IVH, hemiparesis of the right diaphragm, and pulmonary hypertension. Additionally, her baby required multiple surgeries for hemiparesis of the right diaphragm, which resulted in a longer admission. These medical complications were not recognized as influential in her ability to mother. This leads to question whether health literacy had a role in her ability to explain the reason for her baby's admission to the hospital. However, she spoke about being able to complete mothering occupations with minimal support from the medical staff. The doing of engaging in mothering occupations appeared to influence her sense of well-being, which is supported by the definition of doing by Wilcock and Hocking (2015). Erica was able to describe how OT, PT, and ST assisted her in learning how to facilitate various

developmental skills for her baby. The therapeutic relationship Erica developed with the neonatal therapy staff was evident in the subtheme of *support for mothering occupations* as she learned invaluable ways to interact with her baby. Due to her ability to work while at the hospital, she was present for all therapy sessions. This consistent presence at the bedside allowed Erica to feel a sense of belonging with the neonatal therapy staff and within the NICU environment. Belonging has been associated with feelings of being connected with others and places (Wilcock & Hocking, 2015), which may have influenced her ability to assume care of her premature infant and improved her self-confidence.

Participant #5 Crystal. Crystal, a Black, 28-year-old, second-time mother was reserved during her interviews. She discussed being a private person who did not really enjoy talking to people she was unfamiliar with, which was evident in her interviews. Crystal was unemployed and relied on her sister to care for her 9-year-old daughter, so she could be at the hospital on a daily basis. She enjoyed being able to perform kangaroo care. The doing of this mothering occupation and co-occupation enabled her to feel an emotional and physical connection to her baby, which was evident in her description of her experience with performing kangaroo care. Doing has been defined as improving one's health and well-being as participating in occupations fulfills a biological need for the mind and body (Wilcock & Hocking, 2015). The subtheme of *cultural influences* became evident during her account of her lived experience of becoming pregnant and being in the NICU. She discussed her struggle of not understanding medical jargon, which often left her feeling frustrated. Her acknowledgement of not understanding terminology showed the significance health literacy has in explaining medical care to mothers in the NICU. She also spoke about feeling more comfortable with performing mothering occupations when her premature infant required less medical care and lower respiratory support, which alludes to the

importance of using layman terms, explaining medical equipment, and providing additional support for mothering occupations in the Level IV NICU.

Participant #6 Amy. Amy, a 27-year-old, Black, first-time mother recounted her experience with being a mother to a premature infant in a Level IV NICU. She had limited support outside of the hospital as the father of her infant was absent, her mother was frequently busy with other responsibilities, and her sister unexpectedly died, which led Amy to feel an increased level of stress, loneliness, and sadness. Amy's narrative of her feelings is highlighted in the theme of *emotional rollercoaster.* She sought out support for learning how to mother her infant from the nurses and therapy staff. The support she received from NICU staff appeared to influence her a sense of belonging. Belonging has been described as an enabler for forming relationships to people and feelings of being part of a place (Wilcock & Hocking, 2015). She often spoke of how the neonatal therapists helped her understand how to support her baby during nursing care to improve his neurodevelopment. Of all the participants, Amy's story was told with great sadness not only for the loss of a normal pregnancy and delivery but also for limited support during a stressful time in her life. Her narrative shows the importance of having improved resources at the hospital level, especially during a worldwide pandemic.

Participant #7 Michelle. Michelle is a 31-year-old, Black, first-time mother, who emphasized the struggle women of color have within the medical community during her interviews. Michelle's account of her lived experience accentuated the theme of *mother's lost voice.* She experienced a great deal of her voice not being heard or not taken seriously during her prenatal care and for the care of her premature infant in the NICU. Her main source of stress while in the NICU included not being able to trust the medical team when she was not present at the bedside and a lack of communication with the medical team. She was also forthcoming in her

story of how cultural differences appeared to affect her satisfaction of care and trust with the medical team. However, she also recognized how the nurses and therapy staff assisted her in becoming comfortable performing mothering occupations in the medical environment. The act of doing mothering occupations eased her feelings of fear and improved her feelings of confidence in the care of her infant. Doing leads to human survival and the ability to adapt to environmental, political, sociological, and biological situations (Wilcock & Hocking, 2015). The support Michelle received from the neonatal staff and nursing staff helped her to learn how to perform mothering occupations and co-occupations in the NICU.

Participant #8 Kristina. Kristina is a 33-year-old, Black, first-time mother who experienced a prolonged struggle to becoming pregnant due to her own medical needs. When she finally became pregnant, she was overjoyed and extremely happy despite experiencing medical complications, which resulted in delivering her infant early. She discussed situations when her own medical needs or concerns were not taken seriously during her prenatal appointments. Her faith and prayer were evident in her narrative of becoming a mother. Becoming has been stated as satisfying one's life role anticipations and for the development of an overall self-image (Wilcock & Hocking, 2015). Kristina stated she wanted nothing more than to become a mother. She was very optimistic in her infant's developmental outcome. Her story was told with great emotion and gratitude of the NICU staff, which became supportive of the theme *unexpected layer to mothering occupations* and subtheme *support for mothering occupations.* She acknowledged the medical staff and therapy staff as paramount in her ability to mother in the NICU. She often became tearful when speaking about her infant and how strong her infant must be to survive in spite of her medical complications. Kristina's dedication to her infant, faith, and

support from her husband were her driving force to be present daily at the bedside, which improved her confidence in caring for her infant.

Overall, despite the demographic differences among the participants, each participant shared the commonality of having a premature infant admitted to a Level IV NICU for a prolonged period of time. Each participant was able to discuss her experience with pregnancy, delivery, and mothering in great detail with a range of emotions. Stress was often discussed due to a variety of circumstances; therefore, it is important for the NICU staff to recognize that stress is an individualized response as every person experiences stress differently. The participants highlighted their experiences with narratives of support and hinderances to mothering occupations. The accounts from the participants of their lived experience of being a mother to a premature infant in a Level IV NICU greatly influenced the development of the themes during the data analysis.

Unanticipated Journey to Becoming a Mother

The first main theme identified in the dissertation study was *unanticipated journey to becoming a mother*. As identified in the occupational theory of human nature, becoming exists through doing, being, and belonging (Wilcock & Hocking, 2015). The participants discussed their experience during their pregnancy, which was unanticipatedly abrupted with preterm labor. This finding was echoed in the literature, which showed how premature birth disrupts the typical progression of entering motherhood (Mercer, 2004), how mothering identity is distorted (Miles et al., 2011), and preparatory occupations to becoming a mother is altered (Gibbs et al., 2016). Each participant's journey to becoming a mother included high-risk specialists, increased number of doctors' appointments, and early admission to the hospital due to their own medical needs.

Women who become pregnant envision a typical journey to becoming a mother: one without multiple medical appointments and admission to the hospital with constant monitoring. They do not envision a premature birth in which their infant will require admission to a NICU and require surgical interventions for survival. These findings are echoed in the literature of mothers who experience stress of the unanticipated event of having a premature infant (Harris et al., 2018). The impact of having additional, stressful medical appointments, and early admission to the delivery hospital may have on the development of mothering identity has yet to be explored in the literature. Many women who have a typical pregnancy often engage in preparatory occupations (Horne et al., 2005) in which multiple doctors' appointments and high-risk specialists are not involved in their prenatal care or delivery plan. The participants often spoke about how they missed out the societal and cultural rituals of having baby showers and pregnancy photo shoots, which are typical preparatory occupations women engage in while awaiting the arrival of their infants. Hence, having a premature infant often resulted in the participants feeling unprepared for motherhood. This theme is supported in the study of mothers of medically fragile premature infants who felt that becoming a mother in a highly medical environment of the NICU was uncharted (Miles et al., 2011).

Once the participants had delivered their premature infants, the medical and surgical interventions required for the infants' survival and the experience of becoming a mother in a medical environment were often shared with a range of emotions. This finding is reflected in the literature of mothers who experience care for medically complex infants in the NICU (Holditch-Davis et al., 2011; Pineda et al., 2018) in which feelings of stress overcome the mothers. Experiencing motherhood and mothering in a medical setting has been portrayed as stressful (Miles et al., 2011) and greatly impedes bonding between the premature infant and the mother

(Provenzi et al., 2017; Sarapat et al., 2017), which is an unforeseen journey to becoming a mother. When applying the concepts of an occupational theory of human nature, every hindrance or barrier for performing mothering occupations may have a negative health consequences, such as decreased feelings of well-being (Wilcock & Hocking, 2015). Although researchers discuss the stress a mother has for having a premature infant in the NICU (Greene et al., 2015; Harris et al., 2018; Holditch-Davis et al., 2015; Miles et al., 2011; Provenzi et al., 2017), the participants also reported stress outside of the NICU, such as returning to work, care for other children at home, having limited support from loved ones, and the impact of COVID-19, which suggests the importance of considering the occupational role changes mothers of premature infants may experience. Individualized stressors affect mothers differently, and higher levels of perceived stress negatively affects a mother's sense of confidence in participating in the care of their infant (Harris et al., 2018).

Many of the participants spoke about being fearful of not being able to connect with their infants or bond with them because they were so small and fragile. The fear of harming the premature infants left the participants feeling as though they were unable to care for their infants, which left the majority of the care to the medical staff. This journey was an unanticipated one to become a mother for the participants as they relinquished caregiving of their infants to the medical staff. The inability to participate in the doing of occupations, which may have a negative impact to health (Wilcock & Hocking, 2015), left the participants feeling hopeless at times. With a range of emotions being conveyed in each of the participant's account of becoming a mother to a premature infant, the development of the second theme emerged: *emotional rollercoaster.*

Emotional Rollercoaster

The second theme to emerge was *emotional rollercoaster*. From the perspective of an occupational theory of human nature, participation in occupation will give a sense of meaning and purpose to humans (Wilcock & Hocking, 2015). Furthermore, participation in occupation is facilitating for the development of identity, which contributes to giving meaning to one's life and a sense of wellbeing (Christiansen, 1999). Being as described by Wilcock and Hocking (2015) is the time when humans spend looking back to the past, present, and envisioning the future, which contributes to a sense of wellbeing. During the interviews, the participants often reported feeling emotions that may have affected their sense of wellbeing. Their sense of wellbeing may have been directly influenced by their ability to engage in mothering occupations. Many of the participants reported limited opportunities to engage in mothering occupations when their premature infants were first born due to life saving medical interventions and the fragility of their babies, which was often reported with feelings of sadness or fear. However, when discussing holding their baby for the first time, the participants appeared to have a greater sense of wellbeing. Therefore, the range of emotions the participants identified during their account of becoming a mother to a premature infant were portrayed as moments of happiness and sadness. The participants felt proud of their premature infants when milestones were met. On the other hand, being fearful and scared of losing their premature infant was also discussed when medical complications occurred.

The medical complexity of the premature infant coupled with the highly technical medical environment often causes a hindrance to mother-infant bonding (Spinelli et al., 2016). Bonding is known to be imperative for long lasting emotional connections which the infant (Sarapat et al., 2017) and improves maternal competence for performing mothering occupations. The participants discussed how they feared that their infants would not recognize them after

being separated from them following birth. One particular participant stated she feared she would not be able to bond with her infant because she was not allowed to touch him at first. However, once her infant made significant medical progress and she was able to assist in caregiving, she stated how he appeared to notice her voice by turning his head toward her, which made her happy.

The up and down emotions of becoming a mother to a premature infant who is hospitalized in a NICU is reflected by Spinelli et al. (2016). Mothers of premature infants in a NICU often feel uncertain, have increased stress, and feel anxious due to the medical complexity of their infants. Mothers may also feel elated and delighted when their premature infants make progress and require a lower level of medical care. However, the mothers may also experience feelings of being isolated and alone during the hospitalization of their premature infant. Moreover, contrary to the findings of a study about the role of the father as a source of support for the mother in the NICU (Sisson et al., 2015), some of the participants in this dissertation study often voiced how they lacked support from the premature infant's father. Hence, many of the mothers lacked social and emotional support from loved ones and looked upon NICU staff for support, which is echoed in a study about the role of peer support for mothers in the NICU (Rossman et al., 2015). In addition, COVID-19 affected visitation at the hospital, which prohibited more than one visitor at the bedside and limited hospital led support group gatherings, which left mothers feeling alone in their journey to becoming a mother to a premature infant. Despite all of the unanticipated events, the emotional impact for mothering was similar in that they all experienced becoming a mother to a premature infant in the NICU with a range of emotions.

Mother's Lost Voice

The third main theme identified in the dissertation study was *mother's lost voice*. Despite extensive research and recommendations for the inclusion of families in all aspects of care in various frames of reference and models of care (Altimier & Phillips, 2013; Coughlin et al., 2009; Frampton et al., 2017; Gibbins et al., 2008; Johnson, 2000), NICU medical care continues to lack full inclusion of families (Craig et al., 2015). A Level IV NICU in an urban setting includes families from a variety of cultural backgrounds, socioeconomic statuses, and educational levels. Hence, medical staff in the NICU should be aware of the influence that culture, community, and socioeconomic status have on mothering (Arendell, 2000; Collins, 1994; Esdaile et al., 2004). The participants appeared to be more aware of the language differences, the racial comments that were made by staff, and their concerns being ignored by the medical staff, which emphasizes the prevalence of how cultural differences between the participants and the medical staff affected their NICU experience. In their seminal work on mothering, Collins (1994) and Arendell (2000) both discussed how ethnic communities influence mothering, how mothers view mothering from their cultural lenses, and how social class affects mothering. Therefore, when probed about how these cultural differences affected mothering, the responses were varied in how they cope and deal with the medical staff who are not from the same cultural background. When applying the concept of belonging from an occupational theory of human nature, the authors stated that feelings of being connected to others and places provided a sense of security and support (Wilcock & Hocking, 2015). The participants often spoke of ways they dealt with feelings of being an outsider. Many of the coping strategies that were reported included writing unknown words down to Google later, ignoring the uncomfortable racial comments to avoid conflict, continuing to attempt to advocate for their baby, and reporting their concerns to leadership staff at the hospital.

When applying the concepts of the PEO model, the person holds many different characteristics, such as personality traits, cultural influences, and emotional attributes (Law et al., 1996). Therefore, the medical staff in a Level IV NICU should consider each mother's culture and past experience in the medical setting when implementing care plans for the premature infant. The participants alluded to the fact that their own medical concerns were not taken seriously by their doctors during prenatal appointments, which was especially true with the Black participants in the dissertation study. One Black participant had to change OBGYN physicians three times before her voice was heard and taken seriously, which led to her being cared for by a fetal specialist and a high-risk doctor. Therefore, the theme of *mother's lost voice* is supported in the literature as inequalities in health care are a direct result of health disparities in minorities, social racism, and economic injustices (Horbar et al., 2019).

In an occupational theory of human nature, a poor sense of well-being and belonging occurs with occupational imbalance, which causes occupational deprivation (Wilcock & Hocking, 2015). Occupational deprivation is described as any situation that prevents, eliminates, or suppresses occupational engagement (Wilcock & Hocking, 2015). The participants discussed feelings of not being heard, which often resulted in their inability to perform mothering occupations. Therefore, the limited opportunities for engaging in mothering may have resulted in occupational deprivation, occupational imbalance, and feelings of decreased well-being. Additionally, the participants felt as if they were not heard when voicing concerns related to the medical care of their premature infants in the NICU, which often left them feeling as if they were not being taken seriously. One participant stated the medical team missed a fractured wrist after she repeatedly voiced concern over multiple occasions that the wrist did not appear normal. In the literature, minority premature infants have been reported to receive inferior care compared

with their White peers, which is supported by studies exploring racial disparity of NICU quality of care (Horbar et al., 2019; Profit et al., 2017). Another factor to their feelings of their voice not being heard was reflected in inconsistent medical care.

Inconsistent medical care often led to frustrations felt by the participants. Despite the recommendation of family-centered developmental care in NICU in which maternal competence, well-being, and maternal health is at the forefront of improved neurobehavioral outcomes of the infants (Burke, 2018; Pineda et al., 2014), the participants reported feeling their concerns were not being heard, especially by unfamiliar medical staff. When a medical staff member who was new to the infant was in charge of its care, the participants sensed the care was not as thorough when medical concerns were missed, or the infant was put through unnecessary tests. This inconsistent care led to the participants questioning the care that was being provided. The questioning of medical staff by the participants may have influenced the nursing staff's level of care and attitude toward the participants. Despite family-centered care being the best practice or gold standard of care in the NICU, the foundational tenets were not being implemented by the NICU staff at times. Nursing staff interferences with mothering occupations made the participants feel unwelcomed and judged. These feelings may elicit a poor sense of belonging, which impacts the development of the maternal role (Avrech Bar et al., 2016), may act as a barrier to presence in the NICU (Reynolds et al., 2013) and may negatively affect the relationship between the mother and the medical staff (Greene et al., 2015). This finding is supported by studies when the authors explored parents' perceptions of nursing staff toward their ability to care for their infant in the NICU (Guillaume et al., 2013) and the power struggle that often ensues between caregivers and nurses as a result of inconsistent care (Gibbs et al., 2010). Often the participants stated one main source of frustration was a lack of communication and

information from the doctors. Consistent and open communication from doctors helped mothers feel at ease is supported in a study regarding the expectations that parents have of medical staff in the NICU (Guillaume et al., 2013). Therefore, a lack of communication or a delay in communication from doctors left the participants feeling uncertain in the care that was being provided.

The subtheme to mother's lost voice was *cultural influences*. The person construct of the PEO model shows the characteristics of each individual which includes spirituality, culture, cognitive, emotional, and physical attributes to name a few (Law et al., 1996). With the person construct in mind, other factors also should be considered, such as overall health and wellbeing of the individual (Law et al., 1996). Per Law et al. (1996) a individuals use their own capabilities and attributes to participate in occupations in the environment for optimal occupational performance. However, when there is a lack of fit between the person-environment-occupation, a decrease in occupational performance emerges (Law et al., 1996), which became evident as a result of the cultural differences between the participants and medical staff. The participants discussed certain cultural differences, which they contributed to influence the care they received in the NICU. The differences ranged from communication styles, race, socioeconomic status, and age of the participants. This finding is supported by a researcher who evaluated the importance of considering the needs of families when providing care in a NICU, especially when there are demographic differences of the family and the medical staff (Mundy, 2010). Participants showed the importance of having medical staff use layman terms and simplifying the information to ensure understanding of the care their premature infant was receiving. Many participants felt left in the dark about not only with their own medical needs while pregnant but also the medical needs of their infants. The lack of communication often left the participants feeling

disempowered and disrespected. Furthermore, the implicit bias, misunderstandings, and a breakdown in communication led to feelings of disconnect, which is supported by researchers who explored culturally competent care in the NICU (Nicholas et al., 2014). These findings are not reflected in the many studies that supported the implementation of family-centered developmental care in the NICU, which shows the inclusion of families in all aspects of care and is considered the gold standard of care (Coughlin et al., 2009; Davidson et al., 2017; Gibbins et al., 2008; Johnson, 2000). When the mother's inclusion in care was deficient, participants began to feel a lack of trust with the medical staff, especially when they felt their voice was not being heard.

A lack of trust impedes the ability for participants to form a positive therapeutic relationship with the medical staff. The concept of cultural humility in occupational therapy and in health care may open up the idea of practitioners acknowledging others' culture as well as their own culture while also recognizing the power dynamics that are present in health care (Agner, 2020). Agner (2020) supported the finding of the importance of *cultural influences* when providing care to premature infants and their mothers in a NICU that is demographically diverse. Moreover, participants felt as if they could not rely on the nurses to provide appropriate care when they were not at the bedside, which brought about feelings of stress and worry for many of the participants. Another aspect of having a lack of trust was the unprofessional behavior of the nursing staff at times. The unprofessional behavior often presented itself as poor communication styles, use of inappropriate language, and racially insensitive comments. It can be concluded that feelings of disrespect, lack of trust, and disempowerment could act as a barrier to mothering occupations in the NICU. Consequently, there is importance in having parent mentors or support groups in the Level IV NICU for mothers of premature infants.

Roadblocks to Mothering

The fourth main theme of the dissertation study was *roadblocks to mothering*. The natural progression to motherhood is terminated by premature birth, which leads the mother to feel ill-prepared in becoming a mother in the highly technical environment of the NICU (Miles et al., 2011). Furthermore, the medical complexity of the premature infant and the prolonged separation from the infant becomes a barrier to mothering (Spinelli et al., 2016). These barriers to mothering directly affects a mother's sense of wellbeing, which is described by the concepts of doing, being, belonging, and becoming of an occupational theory of human nature (Wilcock & Hocking, 2015). Due to the medical status of the premature infant, nurses often assume the doing of care, which leaves the mothers feeling as if they do not have a role in the care for their infant (Obeidat et al., 2009). Mothers may also feel overwhelmed and stressed which may impact their perception of being and belonging in the NICU (Greene et al., 2015). Also, the sense of becoming a mother may be delayed due the early separation of the premature infant, prolonged separation from the infant, feelings of losing control, and being excluded in the care of their infant (Obeidat et al., 2009). In the seminal work of Ruddick (1995), mothering or a mother's work is viewed as gender expectations for caring for children, being responsible for their upbringing, and safeguarding them from harm, which was prominent in the accounts of the participants being able to care for their premature infants, however, mostly with the support from the medical staff. Ruddick (1995) explained the importance of mother's work as it fosters growth, which is culturally specific, and it serves as feedback for mother's competence. Therefore, when a mother's work is provided by medical staff, it may lead to the mother feeling as though she has failed (Ruddick, 1995).

An occupational disruption occurs due to the barriers for presence and participation, which directly affects mothering (Gibbs et al., 2010). Participants stated many different reasons for limited presence at the bedside, which affected their ability to perform mothering occupations. The finding of *roadblocks to mothering* is supported by many authors when identifying the barriers to bedside presence (Feeley et al., 2016; Pineda et al., 2018; Reynolds et al., 2013; Wigert et al., 2010), which affected mothering and mothering occupations. The authors of an occupational theory of human nature discussed how the inability to engage in occupations may lead to poor health and decreased sense of well-being (Wilcock & Hocking, 2015), which may affect not only mothers but also the long-term developmental needs of premature infants. Family responsibilities outside of the NICU was a reason for decreased presence at the bedside. The participants who had other children often felt torn between being at the hospital and home, which led to them feeling guilty. Returning to work was also a concern and a reason for stress for the participants. With the prevalence of COVID-19 in the community, the participants worried about exposure to not only themselves but also to their medically fragile infant. Another barrier to bedside presence was the distance from the hospital and the participants' homes. Not all of the participants utilized the hospital resources, which supported their ability to be at the hospital. The hospital provided sleep pods outside of the NICU for those who lived less than 49 miles from the hospital or access to the Ronald McDonald House for those who lived more than 49 miles from the hospital.

Another *roadblock to mothering* that occurred was a change in the hospital's visitation policy due to COVID-19. The visitation policy allowed only one caregiver to be present at the bedside. A second caregiver could be identified and allowed to be at the bedside to be exchanged with the primary caregiver every 24-hours, which affected mothering as participants who had

children at home and who did not have social and family support could not visit as often due to lack of childcare. Also, participants discussed how the new hospital visitation policy due to COVID-19 prohibited the family of being together at the bedside and barred extended family members from visiting. The new hospital visitation policy due to COVID-19 goes against the literature recommendations for family-centered developmental care (Coughlin et al., 2009; Craig et al., 2015; Gibbins et al., 2008) in which the family should have 24-hour access to its infant, which is central to the medical care of the premature infant and for their long-term developmental outcomes.

When considering the PEO model of care (Law et al., 1996), the environment of the NICU may be perceived as an overwhelming place for mothers (Gibbs et al., 2010). The environment of the NICU is made up of not only the physical environment but also the medical staff within the environment. Therefore, one can assume the physical environment of the NICU inflicts feelings of stress not only for the mother but also for the premature infant. Many authors have reported that the NICU environment presents a significant barrier to performing mothering occupations due to the intimidating medical equipment as well as the medical staff acting as gate keepers to the infants (Gibbs et al., 2010; Reynolds et al., 2013). The participants discussed missed opportunities for mothering in the NICU. The missed opportunities to mother their premature infant was often due to the medical fragility of the infants but also due to the participants' health following birth. Nursing staff often performed the majority of care for the premature infants, which led to the mother's feeling as though they were in the way and did not feel like a mother to the infant. This concept of missed opportunities to perform mothering occupations and the impact it has on mothering identity is reflected in many studies (Gibbs et al., 2016; Holditch-Davis et al., 2011; Miles et al., 2011). A lack of bedside space in the NICU also

served as a roadblock to mothering. Participants felt as though the limited space affected their ability to comfortably perform skin to skin care. The participants stated the lack of space at the bedside affected access to the premature infant, especially when the nurses and the participants performed caregiving activities together. The bedspace was described as small due to the medical equipment and large furniture in the semi-private area, which posed as an obstacle to performing mothering occupations with assistance from medical staff. On the contrary, participants in private rooms felt as though the rooms were bigger and had more privacy. However, participants in private rooms had limited social interactions compared with the semi-private and open-bay rooms. These finding are supported in the literature by identifying the benefits and challenges between different type of bedspaces in a NICU (Pineda et al., 2012). Overall, the participants were open to discussing the many roadblocks they endured to mothering in their premature infant in a Level IV NICU.

Unexpected Layer to Mothering Occupations

The fifth main theme of the dissertation study was *unexpected layer to mothering occupations*. The unplanned occurrence of having a premature birth changes the typical experience a mother has when having a newborn baby (Gibbs et al., 2010). This unplanned occurrence from a normal pregnancy and delivery often impedes the development of a mothering identity and the maternal role (Holditch-Davis et al., 2011). Hence, mothers experience an impact to their maternal role when mothering co-occupations, such as bathing, feeding, and dressing their premature infant, are often performed by medical staff, which is an unexpected layer to mothering occupations. An important aspect to mothering occupations in the NICU is learning how to perform caregiving activities for the medically fragile premature infants. As identified in the PEO model, the occupational therapist must consider a person's abilities, the

occupations, and the environment in which an individual will be engaging in occupations (Law et al., 1996). Mothering is often viewed as caregiving activities for infants and children that consist of bathing, feeding, and dressing (Horne et al., 2005; Sethi, 2019) and may also be considered a mother's work (Ruddick, 1995). These occupations and co-occupations of mothering newborns often do not include lifesaving medical equipment and the plethora of medical staff. Another aspect of the mothering role that was evident in the participant's account of becoming a mother to a premature infant was that of advocacy. The participants recounted situations when they had to advocate for the care of their infant, which was an unforeseen layer to mothering occupations in the NICU. Therefore, mothers of premature infants often experience additional layers to mothering occupations in the NICU environment. These unexpected layers often require mothers to learn to navigate the NICU, medical staff, and learn new ways of performing mothering occupations and co-occupations.

Mothering occupations that were often discussed were the activities that gave the participants a sense of being the mother, such as decorating the bedspace, which is supported by the concept of being as defined by an occupational theory of human nature in which occupations allow for presentation of personality and feelings of satisfaction (Wilcock & Hocking, 2015). The co-occupations that were discussed involved the activities for caring for their premature infants. During the interviews, the participants provided details about how they learned to care for their premature infants through participation in co-occupations. The participants acknowledged how they received help with learning how to perform co-occupations and facilitation of developmental skills for their infants from the NICU staff, which included nurses, OT, PT, and ST. The medical complexity of the premature infants added an additional obstacle to engaging in co-occupations as medical equipment and the hospital's physical and cultural

environment often posed a barrier. Despite the medical equipment, the participants were able to engage in co-occupations with their premature infants when the premature infants required fewer medical interventions, which helped them with bonding. The co-occupations that were most important to the participants were skin-to-skin holding, changing diapers, taking temperatures, and bathing. The mothering occupations and co-occupations with their infants often gave the participants a sense of normalization within the medical environment. These findings are supported in the literature of the importance of engaging in mothering occupations (Gibbs et al., 2016) and participating in the bedside care with the NICU staff (Pineda et al., 2018).

With premature birth, mothers are often left feeling grief and sadness to the loss of their perfect pregnancy and delivery experience. However, participants discussed how they were attempting to plan events or participate in activities to make their experience in the NICU feel normal, which was an unforeseen aspect of being a mother in the NICU. Normalization activities and mothering occupations that helped the participants were journaling, scrapbooking, and decorating the bedspaces. Participating in these mothering occupations that made the participants feel better, reduce stress, and alleviate anxiety, which is an important aspect to becoming a mother in the NICU. As stated in an occupational theory of human nature, becoming happens as a result of engaging in occupations that allow for being, doing, and belonging (Wilcock & Hocking, 2015). However, mothers of premature infants often miss out on preparatory occupations highlighting pregnancy and delivery milestones. In contrast, the participants often engaged in occupations in the NICU that served as a way to commemorate the premature infant's achievements, such as celebrating their birth date, removal of the breathing tube, or receiving their first tub bath. As identified in the occupational theory of human nature, engaging in occupation is the way humans survive, facilitate health, and support a sense of well-being

(Wilcock & Hocking, 2015). Additionally, engaging in mothering occupations supports the becoming concept of the occupational theory of human nature as it facilitates the process of transformation, maturation, and the realization of one's potential (Wilcock & Hocking, 2015). Becoming comfortable within the medical environment was described as a facilitator to mothering occupations. One must consider the medical environment and how it can both support and hinder mothering occupations. When applying the concepts of the PEO model, the environment has a significant role in occupational performance (Law et al., 1996). Therefore, accommodating space at the bedside to allow for skin to skin to occur would not only benefit the mother but also the nursing staff, so there is no impeding obstacle to gain access to the premature infant. These findings are supported in the literature when discussing the environmental impact the NICU has to engaging in mothering occupations (Gibbs et al., 2010).

The subtheme to unexpected layer to mothering occupations was *support for mothering occupations,* which not only was from the medical staff but also from the NICU environment. Considering the PEO model, optimal occupational performance relies on the person-environment-occupation fit (Law et al., 1996). When applying the PEO model to the NICU, Gibbs et al. (2010) discussed various barriers to parental occupational performance. Many of the barriers involved the physical and cultural environments, such as the medical equipment, hospital rooms, hospital visitation policies, poor communication with staff, and staff assuming the caregiving role. However, contrary to Gibbs et al. (2010), the participants reported having nursing staff as a mentor was an important factor with mothering occupations in the NICU. Nursing staff as a mentor was described as one who facilitated care at the bedside with the participants, encouraged hands on care with nursing staff, facilitated skin-to-skin holding, and acted as a liaison to the doctors, which was most successful with participants who had a primary

nurse assigned to the care of their premature infant. The primary nursing staff concept is identified in the primary nursing care model literature as a way for patients to get consistent nursing care throughout their hospitalization (Pitkanen & Mattila, 2013). Participants discussed the importance of having consistent medical staff with the care of their premature infants not only with nursing staff but also with therapy staff and physicians.

Hospital resources also had a role in supporting mothering occupations in the NICU, which was included in the *support for mothering occupations* subtheme. The Level IV NICU in this dissertation study consisted of child life specialists, social workers, lactation services, and the chaplain, which all supported the mothers with engaging in mothering occupations at the bedside of their premature infants. Other hospital resources to mention are discounted parking, meal tickets in the cafeteria, and sleep pods located outside of the NICU. These hospital resources were used for the participants to remain at the hospital for extended periods of time. The hospital also included all the items needed to care for the premature infants, such as pacifiers, diapers, clothing, bedding, and positioning aids. These items of care were all mentioned by the participants as unexpected accessories that the hospital included, which allowed the participants to engage in mothering occupations.

Implications for Practice

Occupational therapists have provided assessment and interventions to premature infants and their families in the NICU setting for many years and are supported by the AOTA (2018). This dissertation research has implications for occupational therapy practice with mothers of premature infants in a Level IV NICU. Occupational therapists have a unique perspective when considering the importance of engaging in mothering occupations, and the impact these occupations have on a mother's health and wellbeing. Moreover, the importance of facilitating

mothering occupations in the medically complex environment of the NICU to improve mothering identity and the mothering role are highlighted in this dissertation study.

In the Level IV NICU in a pediatric hospital, care for the premature infant is often the focus of occupational therapy practice. Therefore, the findings of this dissertation study were supportive in the implementation of occupation-based practice, focusing on co-occupations between mothers and their premature infants. The findings of this dissertation study were supportive in the role of occupational therapists facilitating mothering occupations in a medically complex environment and focusing on the baby as an integral part of the family unit. Occupational therapists can begin to support opportunities for mothering occupations by adapting the environment of the premature infants' bedspace and by facilitating co-occupations between the mother and her infant. Hence, occupational therapists may provide interventions toward improving an emotional connection between the mother and her premature infant by facilitating bonding interactions through co-occupations. These bonding interactions through co-occupations between the mother and her infant also plays a significant role in the infant's mental health and long-term developmental outcomes, which is supported by the PEO model of care (Law et al., 1996) in which adaptations to the environment improves occupational performance and the occupational theory of human nature (Wilcock, 1993) when doing, being, belonging, and becoming improves the health and wellbeing of individuals. Occupational therapists have the ability to provide interventions directed toward improving the quality of mothering occupations and increasing the opportunities for mothering co-occupations, which could include adaptations to mothering occupations and co-occupations based on the premature infant's needs. By identifying the barriers to mothering occupations and co-occupations, the occupational therapist could tailor interventions to facilitate engagement through adaptations to the NICU environment.

Occupational therapists could also create an educational and training program for mothers in the NICU that focuses on how to perform mothering occupations and co-occupations in the medically complex environment. A wide range of topics could be included, such as infant massage, how to read infant cues, ways to facilitate motor skills by improving handling skills, how to engage in co-occupations, and ways to facilitate mother-infant bonding. Furthermore, occupational therapists could serve as a point of contact for providing education geared toward preparation to discharge home to assist in a smooth transition from the NICU to the mothers' homes.

Occupational therapists could also advocate for the mothers of premature infants in the Level IV NICU to improve all areas of family-centered developmental care. The Level IV NICU would benefit from adding parent mentors to not only serve as a support for the mothers but also as an advocate for the mothers within the medical setting. Occupational therapists may serve as the facilitator to strengthening family-centered care, implementing guidelines for the inclusion of the family in all aspects of care, and highlighting the importance of cultural humility to individualize care for each family unit. Therefore, understanding the impact of cultural humility, occupational therapists could lead the way in improving the care that mothers from diverse demographic backgrounds receive in the NICU thus improving satisfaction of care in the NICU. Providing education and training to all medical staff on cultural humility could be a focus of occupational therapy as part of the multidisciplinary team. This training could begin with providing education to all new hires of NICU staff as well as existing staff. Education and training that includes the importance of mothering occupations, how to facilitate mothering occupations, how to facilitate co-occupations, and highlighting the importance of the maternal role could also be included for NICU staff.

Implications for Future Research

The focus of this hermeneutic phenomenological study was to explore the lived experience of mothers of premature infants in a Level IV NICU and to explore the experience of performing mothering occupations in the NICU. Occupational therapists should consider future research that seeks to gain specific knowledge into mothering occupations of premature infants. Occupational therapists could explore the importance of occupation-based interventions by investigating mother-infant co-occupations in the NICU. Hence, understanding mothering occupations in the medically complex environment of a Level IV NICU to care for medically fragile premature infants should be considered for future investigations.

Future research may also include how mothers of premature infants in a Level IV NICU in an urban setting perceive family-centered developmental care practices with an emphasis on cultural humility due to the demographic differences of each mother, which would be to further explore mother's lost voice in mothering occupations in the NICU. Mothering occupations from the perspective of different cultural backgrounds may help strengthen occupational therapy assessment and interventions in the NICU. Occupational therapists may improve cultural humility and family-centered developmental care practices by applying other occupational therapy theoretical frameworks and models of care, such as occupational justice (Townsend & Wilcock, 2004) and the Kawa model (Iwama et al., 2009) in researching mothering occupations in the NICU. Future research may also include developing unique theories and models of care specifically for mothering, mothering occupations, and co-occupations in the NICU.

Future research in understanding how mothers perceive support from medical staff when engaging in mothering occupations would benefit all medical staff in the NICU. Another area for future research would be seeking to understand a mother's need for support from allied health,

ancillary services, and support staff in the NICU, which would assist in specific training and educational programs, which could include identifying any resources to overcome environmental barriers to mothering occupations. Future research on having a primary OT assigned to each mother and her infant would gain more knowledge about how consistent care improves mothering and mothering occupations in the NICU.

Implications for Public Policy

The focus of this hermeneutic phenomenological study was to explore the lived experience of mothers of premature infants in a Level IV NICU and to explore the experience of performing mothering occupations in the NICU. The findings of this dissertation study showed that a Level IV NICU in an urban setting consists of mothers and their premature infants from variety of cultural backgrounds, different socioeconomic statuses, and varied educational backgrounds. This finding is reflected in many studies regarding the demographics of families in the NICU (Holditch-Davis et al., 2015; Horbar et al., 2019; Profit et al., 2017). Occupational therapists should recognize the barriers from the social and economic barriers that affect the lives of mothers of premature infants in a Level IV NICU. Occupational therapists could develop a multidisciplinary team with a goal of creating a resource packet for mothers who need assistance due to social and economic barriers.

It is important to understand that these barriers are supporting the occupational therapist in leading the way to change hospital policies that improves the experience of mothers of premature infants. Occupational therapists could partner with families to obtain their perspectives about how to improve care within the NICU by identifying their priorities. The Level IV NICU may benefit from adding a patient and family advisory council (PFAC) to improve communication and relationships between the families and NICU staff. More

specifically, exploring the hospital policies in response to a worldwide pandemic that would be of importance to mothers of premature infants in the NICU. Hospital visitation policies should be modified to allow more than one caregiver at the NICU bedside at the same time. Also, allowing siblings to be present throughout the hospital stay could improve mother's presence at the bedside. Another factor to improving mothering in the Level IV NICU at the hospital level would be to investigate the diversity of the medical staff and to advocate for change of the recruiting and hiring process to ensure diversity and inclusion of all cultures and races of the medical staff. Furthermore, occupational therapists with the understanding of environmental, social, and personal barriers to bedside presence could advocate for the use of telehealth technology in the hospital setting. Telehealth technology can be used to help mothers with premature infants admitted to the NICU for prolonged admissions be more engaged, bond, and provide education to bridge the gap between the hospital and home. Additionally, advocating for the use of telehealth technology at the hospital policy level could also improve occupational engagement of mothers who have barriers to bedside presence.

The impact of public policy of parental leave policy and the Family and Medical Leave Act (FMLA) on mothering occupations in a Level IV NICU and on maternal bedside presence during prolonged admissions should be explored. The United States has a high rate of prematurity, especially among low-income and minority populations in which unpaid leave is more likely following the birth of a newborn (Greenfield & Klawetter, 2016). The need for continuing to work for not only living expenses but also for health insurance often acts as a barrier to frequent and consistent bedside presence of mothers. Many mothers returned to work early following the birth of their premature infant to save time off when the infant was ready for discharge. This absence of presence over a prolonged admission may affect not only mothering

occupations and mothering identity but also on long-term neurodevelopmental outcomes of the premature infant. Therefore, occupational therapists have a role in advocating for policy changes at the state and federal level to mandate paid parental leave for the care of premature infants in the NICU.

Limitations

A hermeneutic, phenomenology philosophical method of inquiry includes seeking to understand the lived experiences of individuals in their everyday lives (Cohen et al., 2000). The use of the hermeneutic phenomenology method is often used to gain a better understanding of phenomena (Cohen et al., 2000). While this type of method has its strengths, there are also limitations. One limitation is that the findings cannot be generalized to the general population. However, generalization was not the aim of this dissertation study. The population and sample size were chosen as supported by hermeneutic phenomenological method, which was achieved with eight mothers of premature infants in a Level IV NICU.

The second limitation was the occurrence of a worldwide pandemic, COVID-19, and its impact on the data collection process. Recruiting participants was difficult due to the new hospital visitation policy in response to COVID-19. The use of personal protective equipment due to COVID-19 affected the data collection process as nonverbal body language was difficult to notate with face coverings in place. The length of each individual interview was also affected by COVID-19 due to the small size of the conference room in the NICU and participants appearing to not want to remain in close contact with the investigator, which was evident in their length of time of each interview.

The third limitation of the dissertation study was the investigator's clinical and research role in the NICU. The investigator was a member of the NICU therapy team and provided direct

clinical services to the premature infants and their mothers. The investigator was also the only member conducting this research study; therefore, blurring of roles occasionally occurred during the data collection process. Bracketing became a very critical aspect of the data collection process to ensure acknowledgement of biases. Participants may also have been withholding of their account of their experiences due to the dual roles the investigator had in the NICU.

Summary

This hermeneutic phenomenological study was used to explore the lived experience of mothers of premature infants in a Level IV NICU. Individual, semi-structured interviews showed in-depth accounts of the experiences of mothers of premature infants in the NICU. In this dissertation study, eight participants gave descriptions of their experiences with mothering occupations for their premature infants in the medically complex environment of the NICU. The findings showed that the participants experienced similarities, which the investigator organized into five themes: *unanticipated journey to becoming a mother, emotional rollercoaster, mother's lost voice, roadblocks to mothering,* and *unexpected layer to mothering occupations*. This investigator explained how occupational therapists are in a unique position to foster mothering occupations and mother-infant co-occupations in the NICU. Additionally, this dissertation study has highlighted the importance of implementing occupation-based practice in the NICU when occupational therapists can facilitate mother-infant co-occupations for the health and wellbeing of mothers and their premature infants. Occupational therapists are an important member of the NICU medical team for developing education, training, and intervention programs for mothers of premature infants from diverse backgrounds. This investigator highlighted the importance for providing support and resources for mothers with varying needs outside of the hospital. The findings from this dissertation study also showed how cultural humility should be included in

family-centered developmental care in the NICU. Cultural humility education and training should be a part of all new hire orientation and for existing team members in the NICU to improve the satisfaction and inclusion in care for all mothers. Occupational therapists may also serve as an advocate for public policy and hospital policy changes for support and resources for mothers of premature infants in the NICU.

Postscript

Mothers of premature infants in a Level IV NICU experience in becoming a mother to a fragile infant in a complex, medical environment was discussed. The medical fragility of the premature infant has an added layer for the importance of supporting mothers during the hospitalization. Supporting mothers in becoming the mother they want to be to their premature infant in the NICU is of upmost importance as this experience may be the only time they have with their infant. During this dissertation study and following the conclusion of this dissertation study, a total of four of the eight participants' infants died either while in the NICU, in the technology-dependent intensive care unit (TDICU), or at home once discharged from the hospital. With this outcome in mind, occupational therapists should foster every opportunity to facilitate mothering occupations and co-occupations between mothers and their premature infants. Additionally, focusing on the mother's needs, desires, and wants for herself and her baby as well as including her in all aspects of care should be paramount in family-centered developmental care practices in the NICU. The importance of recognizing the probability of an infant's death whether in the NICU or following discharge home from the hospital should be in the forefront of neonatal care practices to ensure the mother's lived experience of mothering is celebrated, honored, and memorable.

References

Agner, J. (2020). Moving from cultural competence to cultural humility in occupational therapy: A paradigm shift. *American Journal of Occupational Therapy, 74*(4), Article 7404347010 doi:10.5014/ajot.2020.038067

Al Maghaireh, D. F., Abdullah, K. L., Chan, C. M., Piaw, C. Y., & Al Kawafha, M. M. (2016). Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit. *Journal of Clinical Nursing, 25*(19-20), 2745-2756. doi:10.1111/jocn.13259

Als, H. (1982). Toward a synactive theory of development: Promise for the assessment and support of infant individuality. *Infant Mental Health Journal, 3*(4), 229-243.

Als, H. (1986). A synactive model of neonatal behavioral organization. *Physical & Occupational Therapy In Pediatrics, 6*(3-4), 3-53. doi:10.1080/J006v06n03_02

Altimier, L. (2015). Neuroprotective core measure 1: The healing NICU environment. *Newborn and Infant Nursing Reviews, 15*, 91-96.

Altimier, L., & Phillips, R. M. (2013). The neonatal integrative developmental care model: Seven neuroprotective core measures for family-centered developmental care. *Newborn and Infant Nursing Reviews, 13*(1), 9-22. doi:10.1053/j.nainr.2012.12.002

American Academy of Pediatrics. (2004). Age terminology during the perinatal period. *Pediatrics, 114*(5), 1362-1364.

American Academy of Pediatrics. (2012). Levels of neonatal care. *Pediatrics, 130*(3), 587-597.

American Academy of Pediatrics. (2017). *Guidelines for Perinatal Care* (8th ed.). The American Academy of Pediatrics.

American Occupational Therapy Association. (2018). Occupational therapy's role in the neonatal intensive care unit. *American Journal of Occupational Therapy, 72*, Article 7212410060.

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy, 74*, Article 7412410010. https://doi.org/10.5014/ajot2020.74S2001

Arendell, T. (2000). Conceiving and investingating motherhood: The decade's scholarship. *Journal of Marriage and the Family, 62*, 1192-1207.

Avrech Bar, M., Forwell, S., & Backman, C. L. (2016). Ascribing meaning to occupation. *Occupation, Participation & Health, 36*(3), 148-158. doi:10.1177/1539449216652622

Barbosa, V. M. (2013). Teamwork in the neonatal intensive care unit. *Physical & Occupational Therapy in Pediatriacs, 33*(1), 5-26. doi:10.3109/01942638.2012.729556

Barrett, J., & Fleming, A. S. (2011). Annual research review: All mothers are not created equal: Neural and psychobiological perspectives on mothering and the importance of individual differences. *Journal of Child Psychology & Psychiatry, 52*(4), 368-397. doi:10.1111/j.1469-7610.2010.02306.x

Baum, N., Weidberg, Z., Osher, Y., & Kohelet, D. (2012). No longer pregnant, not yet a mother: Giving birth prematurely to a very-low-birth-weight baby. *Qualitative Health Research, 22*(5), 595-606. doi:10.1177/1049732311422899

Burke, S. (2018). Systematic review of developmental care interventions in the neonatal intensive care unit since 2006. *Journal of Child Health Care, 22*(2), 269-286.

Butt, M. L., McGrath, J. M., Samra, H., & Gupta, R. (2013). An integrative review of parent satisfaction with care provided in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 42*(1), 105-120. doi:10.1111/1552-6909.12002

Cabrera, J. P. (2018). Maternal role attainment theory: Promoting maternal identity and family health. *International Journal of Childbirth Education, 33*(2), 21-23.

Cardin, A. D. (2020). Parents' perspectives: An expanded view of occupational and co-occupational performance in the neonatal intensive care unit. *American Journal of Occupational Therapy, 74*(2), 1-12. doi:10.5014/ajot.2020.034827

Chodorow, N. (1978). *The reproduction of mothering: Psychoanalysis and the sociology of gender*. University of California Press.

Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy, 53*(6), 547-558.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers*. Sage Publications, Inc.

Collins, P. H. (1994). Shifting the center: Race, class, and feminist theorizing about motherhood. In E. N. Glenn, G. Chang, & L. R. Forcey (Eds.), *Mothering: Ideology, experience, and agency* (pp. 45-65). Taylor & Francis Group, LLC.

Coughlin, M., Gibbins, S., & Hoath, S. (2009). Core measures for developmentally supportive care in neonatal intensive care units: Theory, precedence and practice. *Journal of Advanced Nursing, 65*(10), 2239-2248. doi:10.1111/j.1365-2648.2009.05052.x

Craig, J. W., Glick, C., Phillips, R., Hall, S. L., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology, 35*(Suppl. 1), S5-S8. doi:10.1038/jp.2015.142

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Sage Publications, Inc.

Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., Cox, C. E., Wunsch, H., Wickline, M. A., Nunnally, M. E., Netzer, G., Kentish-Barnes, N., Sprung, C. S., Hartog, Coombs, M. Gerritsen, R. T., Hopkins, R. O., Frank, L. S., Skrobik, Y., . . . Curtis, J. R. (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Critical Care Medicine, 45*(1), 103-128.

Dunbar, S. B. (Ed.). (2007). *Occupational therapy models for intervention with children and families*. Slack, Inc.

Dunbar, S. B., & Roberts, E. (2006). An exploration of mothers' perceptions regarding mothering occupations and experiences. *Occupational Therapy in Health Care, 20*(2), 51-73. doi:10.1300/J003v20n02_04

Esdaile, S. A., Farrell, E. A., & Olson, J. A. (2004). Anticipating occupations of mothering and the development of agency. In S. A. Esdaile, & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 3-27). F. A. Davis Company.

Feeley, N., Genest, C., Niela-Vilén, H., Charbonneau, L., & Axelin, A. (2016). Parents and nurses balancing parent-infant closeness and separation: A qualitative study of NICU nurses' perceptions. *BMC Pediatrics, 16*, 1-13. doi:10.1186/s12887-016-0663-1

Fraga, E., da Silva Dittz, E., & Guimarães Machado, L. (2019). The construction of maternal co-occupation in the neonatal intensive care unit. *Brazilian Journal of Occupational Therapy/Cadernos Brasileiros de Terapia Ocupacional, 27*(1), 92-104. doi:10.4322/2526-8910.ctoAO1125

Frampton, S. B., Guastello, S., Hoy, L., Naylor, M., Sheridan, S., & Johnston-Fleece, M. (2017). Harnessing evidence and experience to change culture: A guiding framework for patient

and family engaged care. *NAM Perspectives*. National Academy of Science. https://doi.org/10.31478/201701f

Francis-Connolly, E. (2000). Toward an understanding of mothering: A comparison of two motherhood stages. *American Journal of Occupational Therapy, 54*(3), 281-289.

Francis-Connolly, E. (2004). Mothering across the lifespan. In S. A. Esdaile, & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 153-171). F. A. Davis Company.

Francis-Connolly, E. (2009). It never ends: Mothering as a lifetime occupation. *Scandinavian Journal of Occupational Therapy, 5*(3), 149-155. doi:10.3109/11038129809035740

Franck, L. S., & Spencer, C. (2003). Parent visiting and participation in infant caregiving activities in a neonatal unit. *Birth: Issues in Perinatal Care, 30*(1), 31-35.

Frank, G., & Polkinghorne, D. (2010). Qualitative research in occupational therapy: From the first to the second generation. *Occupation, Participation and Health, 30*(2), 51-57. doi:10.3928/15394492-20100325-02

Gibbins, S., Hoath, S. B., Coughlin, M., Gibbins, A., & Franck, L. (2008). The universe of developmental care: A new conceptual model for application in the neonatal intensive care unit. *Advances in Neonatal Care, 8*(3), 141-147.

Gibbs, D., Boshoff, K., & Lane, A. (2010). Understanding parenting occupations in neonatal intensive care: Application of the person-environment-occupation model. *The British Journal of Occupational Therapy, 73*(2), 55-63. doi:10.4276/030802210x12658062793762

Gibbs, D., Boshoff, K., & Stanley, M. (2015). Becoming the parent of a preterm infant: A meta-ethnographic synthesis. *British Journal of Occupational Therapy, 78*(8), 475-487. doi:10.1177/0308022615586799

Gibbs, D. P., Boshoff, K., & Stanley, M. J. (2016). The acquisition of parenting occupations in neonatal intensive care: A preliminary perspective. *Canadian Journal of Occupational Therapy, 83*(2), 91-102. doi:10.1177/0008417415625421

Glenn, E. N. (1994). Social constructions of mothering: A thematic overview. In E. N. Glenn, G. Chang, & L. R. Forcey (Eds.), *Mothering: Ideology, experience, and agency* (pp. 1-29). Taylor & Francis Group, LLC.

Gonya, J., & Nelin, L. D. (2013). Factors associated with maternal visitation and participation in skin-to-skin care in an all referral level IIIc NICU. *Acta Paediatrica, 102*(2), e53-56. doi:10.1111/apa.12064

Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L. S., Howse, J. L., & Berns, S. D. (2011). Family support and family-centered care in the neonatal intensive care unit: Origins, advances, impact. *Seminars in Perinatology, 35*(1), 20-28. doi:10.1053/j.semperi.2010.10.004

Graven, S., & Brown, J. (2008). Sensory development in the fetus, neonate, and infant: Introduction and overview. *Newborn and Infant Nursing Reviews, 8*(4), 169-172.

Greene, M. M., Rossman, B., Patra, K., Kratovil, A., Khan, S., & Meier, P. P. (2015). Maternal psychological distress and visitation to the neonatal intensive care unit. *Acta Paediatrica, 104*(7), e306-313. doi:10.1111/apa.12975

Greenfield, J. C., & Klawetter, S. (2016). Parental leave policy as a strategy to improve outcomes among premature infants. *Health & Social Work, 41*(1), 17-23. doi:10.1093/hsw/hlv079

Guillaume, S., Michelin, N., Amrani, E., Benier, B., Durrmeyer, X., Lescure, S., Bony, C., Danan, C., Baud, O., Jarreau, P.-H., Zana-Taieb, E., & Caeymaex, L. (2013). Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: A qualitative multicenter study with 60 parents. *BMC Pediatrics, 13*(1), Article 18. doi:10.1186/1471-2431-13-18

Hammell, K. R. W. (2013). Occupation, well-being, and culture: Theory and cultural humility *Canadian Journal of Occupational Therapy, 80*(4), 224-234. doi:10.1177/0008417413500465

Harris, R., Gibbs, D., Mangin-Heimos, K., & Pineda, R. (2018). Maternal mental health during the neonatal period: Relationships to the occupation of parenting. *Early Human Development, 120*, 31-39. doi:10.1016/j.earlhumdev.2018.03.009

Harrison, H. (1993). The principles for family-centered neonatal care. *Pediatrics, 92*(5), 643-650.

Heermann, J. A., Wilson, M. E., & Wilhelm, P. A. (2005). Mothers in the NICU: Outsider to partner. *Pediatric Nursing, 31*(3), 176-186.

Heinemann, A. B., Hellström-Westas, L., & Nyqvist, K. H. (2013). Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room. *Acta Paediatrica, 102*, 695-702.

Hernández, N. L., Rubio Grillo, M. H., & Lovera, A. (2016). Strategies for neonatal developmental care and family-centered neonatal care. *Investigacion & Educacion en Enfermeria, 34*(1), 104-112. doi:10.17533/udea.iee.v34n1a12

Heydarpour, S., Keshavarz, Z., & Bakhtiari, M. (2017). Factors affecting adaptation to the role of motherhood in mothers of preterm infants admitted to the neonatal intensive care unit: A qualitative study. *Journal of Advanced Nursing, 73*(1), 138-148. doi:10.1111/jan.13099

Hoang, A., Chorath, K., Moreira, A., Evans, M., Burmeister-Morton, F., Burmeister, F., Naqvi, R., Petershack, M., & Moreira, A. (2020). COVID-19 in 7780 pediatric patients: A systematic review. *EClinicalMedicine, 24*, Article 100433. doi:10.1016/j.eclinm.2020.100433

Holditch-Davis, D., Miles, M. S., Burchinal, M. R., & Goldman, B. D. (2011). Maternal role attainment with medically fragile infants: Part 2. Relationship to the quality of parenting. *Research in Nursing & Health, 34*(1), 35-48. doi:10.1002/nur.20418

Holditch-Davis, D., Santos, H., Levy, J., White-Traut, R., O'Shea, T. M., Geraldo, V., & David, R. (2015). Patterns of psychological distress in mothers of preterm infants. *Infant Behavior & Development, 41*, 154-163. doi:10.1016/j.infbeh.2015.10.004

Horbar, J. D., Edwards, E. M., Greenberg, L. T., Profit, J., Draper, D., Helkey, D., Lorch, S. A., Lee, H. C., Phibbs, C. S., Rogowski, J., Gould, J. B., & Firebaugh, G. (2019). Racial segregation and inequality in the neonatal intensive care unit for very low-birth-weight and very preterm infants. *JAMA Pediatrics, 173*(5), 455-461. doi:10.1001/jamapediatrics.2019.0241

Horne, J., Corr, S., & Earle, S. (2005). Becoming a mother: A study exploring occupational change in first-time motherhood. *Journal of Occupational Science, 12*(3), 176-183.

Hussein, M. E., Jakubec, S. L., & Osuji, J. (2015). Assessing the FACTS: A mnemonic for teaching and learning the rapid assessment of rigor in qualitative research studies. *The Qualitative Report, 20*(8), 1182-1184.

Iwama, M. K., Thomson, N. A., & Macdonald, R. M. (2009). The Kawa model: The power of culturally responsive occupational therapy. *Disability & Rehabilitation, 31*(14), 1125-1135. doi:10.1080/09638280902773711

Johnson, B., & Abraham, M. (2012). *Partnering with patients, residents, and families: A resource for leaders of hospitals, ambulatory care settings, and long-term care communities*. Institute for Patient-and Family-Centered Care.

Johnson, B. H. (2000). Family-centered care: Four decades of progress. *Families, Systems, & Health, 18*(2), 137-156. doi:10.1037/h0091843

Jorgensen, A. M. (2010). Born in the USA–The history of neonatology in the United States: A century of caring. *NICU Currents*, 1-12.

Klawetter, S., Neu, M., Roybal, K. L., Greenfield, J. C., Scott, J., & Hwang, S. (2019). Mothering in the NICU: A qualitative exploration of maternal engagement. *Social Work in Health Care, 58*(8), 746-763. doi:10.1080/00981389.2019.1629152

Korja, R., Maunu, J., & Lehtonen, L. (2008). Mother-infant interaction is influenced by the amount of holding in preterm infants. *Early Human Development, 84*(4), 257-267.

Korja, R., Latva, R., & Lehtonen, L. (2012). The effects of preterm birth on mother-infant interaction and attachment during the infant's first two years. *Acta Obstetricia et Gynecologica Scandinavica, 91*(2), 164-173. doi:10.1111/j.1600-0412.2011.01304.x

Latva, R., Lehtonen, L., Salmelin, R., & Tamminen, T. (2004). Visiting less than every day: A marker for later behavioral problems in Finnish preterm infants. *Archives of Pediatric and Adolescent Medicine, 158*(12), 1153-1157.

Latva, R., Lehtonen, L., Salmelin, R. K., & Tamminen, T. (2007). Visits by the family to the neonatal intensive care unit. *Acta Paediatrica, 96*(2), 215-220.

Law, M., Cooper, B. A., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupational model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63*(1), 9-23.

Luborsky, M. R., & Lysack, C. (2017). Design considerations in qualitative research. In R. R. Taylor (Ed.), *Kielhofner's research in occupational therapy: Methods of inquiry for enhancing practice* (2nd ed., pp. 180-195). F. A. Davis Company.

Lundqvist, P., Weis, J., & Sivberg, B. (2019). Parents' journey caring for a preterm infant until discharge from hospital-based neonatal home care—A challenging process to cope with. *Journal of Clinical Nursing, 28*(15/16), 2966-2978. doi:10.1111/jocn.14891

Lyons, M., Orozovic, N., Davis, J., & Newman, J. (2002). Doing-being-becoming: Occupational experiences of persons with life-threatening illnesses. *American Journal of Occupational Therapy, 56*(3), 285-295.

Lysack, C., Luborsky, M. R., & Dillaway, H. (2017). Collecting qualitative data. In R. R. Taylor (Ed.), *Kielhofner's resarch in occupational therapy: Methods of inquiry for enhancing practice* (2nd ed., pp. 196-213). F. A. Davis Company.

March of Dimes. (2018). *Peristats*. https://www.marchofdimes.org/peristats/ViewTopic.aspx?reg=13&top=3&lev=0&slev=4

Mazurak, M., & Czyżewska, M. (2006). Incubator doctor and the Dionne quintuplets: On the phenomenon of exhibiting premature infants. *Dental and Medical Problems, 43*(2), 313-316.

Mercer, R. T. (2004). Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship, 36*(3), 226-232. http://dx.doi.org/10.1111/j.1547-5069.2004.04042.x

Miles, M. S., Holditch-Davis, D., Burchinal, M. R., & Brunssen, S. (2011). Maternal role attainment with medically fragile infants: Part 1. Measurement and correlates during the first year of life. *Research in Nursing & Health, 34*(1), 20-34. doi:10.1002/nur.20419

Mirlashari, J., Valizadeh, S., Navab, E., Craig, J. W., & Ghorbani, F. (2019). Dark and bright—Two sides of family-centered care in the NICU: A qualitative study. *Clinical Nursing Research, 28*(7), 869-885. doi:10.1177/1054773818758171

Mundy, C. A. (2010). Assessment of family needs in neonatal intensive care units. *American Journal of Critical Care, 19*(2), 156-163. doi:10.4037/ajcc2010130

Nakra, N. A., Blumberg, D. A., Herrera-Guerra, A., & Lakshminrusimha, S. (2020). Multi-system inflammatory syndrome in children (MIS-C) following SARS-CoV-2 infection: Review of clinical presentation, hypothetical pathogenesis, and proposed management. *Children 7*(7), Article 69. doi:10.3390/children7070069

Neu, M., Robinson, J., & Schmiege, S. J. (2013). Influence of holding practice on preterm infant development. *MCN: The American Journal of Maternal Child Nursing, 38*(3), 136-143. doi:10.1097/NMC.0b01 3e31827ca68c

Nicholas, D. B., Hendson, L., & Reis, M. D. (2014). Connection versus disconnection: Examining culturally competent care in the neonatal intensive care unit. *Social Work in Health Care, 53*(2), 135-155. doi:10.1080/00981389.2013.864377

Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of perinatal education, 18*(3), 23-29. doi:10.1624/105812409X461199

Olson, J. A. (2004). Mothering co-occupations in caring for infants and young children In S. A. Esdaile, & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 28-51). F. A. Davis.

Phelan, S., & Kinsella, E. A. (2009). Occupational identity: Engaging sociocultural perspectives. *Journal of Occupational Science, 16*(2), 85-91.

Pierce, D. (2009). Co-occupation: The challenges of defining concepts original to occupational science. *Journal of Occupational Science, 16*(3), 203-207. doi:10.1080/14427591.2009.9686663

Pierce, D., & Frank, G. (1992). A mother's work: Two levels of feminist analysis of family-centered care. *American Journal of Occupational Therapy, 46*(11), 972-980. doi:10.5014/ajot.46.11.972

Pineda, R., Bender, J., Hall, B., Shabosky, L., Annecca, A., & Smith, J. (2018). Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes. *Early Human Development, 117*, 32-38. doi:10.1016/j.earlhumdev.2017.12.008

Pineda, R., Neil, J., Dierker, D., Smyser, C., Wallendorf, M., Kidokoro, H., Reynolds, L. C., Walker, S., Rogers, C., Mathur, A. M., Van Essen, D. C., & Inder, T. (2014). Alterations in brain structure and neurodevelopmental outcome in preterm infants hospitalized in different neonatal intensive care unit environments. *Journal of Pediatrics, 164*(1), 52-60.

Pineda, R., Raney, M., & Smith, J. (2019). Supporting and enhancing NICU sensory experiences (SENSE): Defining developmentally-appropriate sensory exposures for high-risk infants. *Early Human Development, 133,* 29-35. doi:10.1016/j.earlhumdev.2019.04.012

Pineda, R. G., Stransky, K. E., Rogers, C., Duncan, M. H., Smith, G. C., Neil, J., & Inder, T. (2012). The single-patient room in the NICU: Maternal and family effects. *Journal of Perinatology, 32*(7), 545-551. doi:10.1038/jp.2011.144

Pitkanen, A., & Mattila, E. (2013). The effects of the primary nursing care model: A systematic review. *Journal of Nursing & Care, 03*(6). doi:10.4172/2167-1168.1000205

Price, P., & Miner, S. (2009). Extraordinarily ordinary moments of co-occupation in a neonatal intensive care unit. *OTJR: Occupation, Participation & Health, 29*(2), 72-78.

Price, P., & Stephenson, S. M. (2009). Learning to promote occupational development through co-occupation. *Journal of Occupational Science, 16*(3), 180-186.

Primeau, L. A. (2004). Mothering in the context of unpaid work and play in families. In S. A. Esdaile, & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 115-133). F.A. Davis.

Profit, J., Gould, J. B., Bennett, M., Goldstein, B. A., Draper, D., Phibbs, C. S., & Lee, H. C. (2017). Racial/ethnic disparity in NICU quality of care delivery. *Pediatrics, 140*(3), Article e20170918.

Provenzi, L., Fumagalli, M., Bernasconi, F., Sirgiovanni, I., Morandi, F., Borgatti, R., & Montirosso, R. (2017). Very preterm and full-term infants' response to socio-emotional stress: The role of postnatal maternal bonding. *Infancy, 22*(5), 695-712. doi:10.1111/infa.12175

Raiskila, S., Axelin, A., Toome, L., Caballero, S., Tandberg, B. S., Montirosso, R., Normann, E., Hallberg, B., Westrup, B., Ewald, U., & Lehtonen, L. (2017). Parents' presence and parent-infant closeness in 11 neonatal intensive care units in six European countries vary between and within the countries. *Acta Paediatrica, 106*(6), 878-888. doi:10.1111/apa.13798

Ramezani, T., Shirazi, Z. H., Sarvestani, R. S., & Moattari, M. (2014). Family-centered care in neonatal intensive care unit: A concept analysis. *International Journal of Community Based Nursing & Midwifery, 2*(4), 268-278.

Reynolds, L. C., Duncan, M. M., Smith, G. C., Mathur, A., Neil, J., Inder, T., & Pineda, R. G. (2013). Parental presence and holding in the neonatal intensive care unit and associations with early neurobehavior. *Journal of Perinatology, 33*(8), 636-641. doi:10.1038/jp.2013.4

Richards, L., & Morse, J. M. (2013). *Readme first for a user's guide to qualitative methods* (3rd ed.). Sage Publications, Inc.

Ross, K., Heiny, E., Conner, S., Spener, P., & Pineda, R. (2017). Occupational therapy, physical therapy and speech-language pathology in the neonatal intensive care unit: Patterns of therapy usage in a Level IV NICU. *Research in Developmental Disabilities, 64*, 108-117. doi:10.1016/j.ridd.2017.03.009

Rossman, B., Greene, M. M., & Meier, P. P. (2015). The role of peer support in the development of maternal identity for "NICU Moms." *Journal of Obstetric, Gynecologic & Neonatal Nursing, 44*(1), 3-16. doi:10.1111/1552-6909.12527

Ruddick, S. (1995). *Maternal thinking*. Beacon Press.

Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., & Ayers, S. (2014). Parents' views on care of their very premature babies in neonatal intensive care units: A qualitative study. *BMC Pediatrics, 14*(1), 230-230. doi:10.1186/1471-2431-14-230

Sankar, J., Dhochak, N., Kabra, S. K., & Lodha, R. (2020). COVID-19 in children: Clinical approach and management. *Indian Journal of Pediatrics, 87*(6), 433-442. doi:10.1007/s12098-020-03292-1

Sarapat, P., Fongkaew, W., Jintrawet, U., Mesukko, J., & Ray, L. (2017). Perceptions and practices of parents in caring for their hospitalized preterm infants. *Pacific Rim International Journal of Nursing Research, 21*(3), 220-233.

Sethi, C. (2019). Mothering as a relational role: Re-evaluating everyday parenting occupations. *Journal of Occupational Science,* 1-12. doi:10.1080/14427591.2019.1666423

Sisson, H., Jones, C., Williams, R., & Lachanudis, L. (2015). Metaethnographic synthesis of fathers' experiences of the neonatal intensive care unit environment during hospitalization of their premature infants. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 44*(4), 471-480.

Skene, C., Gerrish, K., Price, F., Pilling, E., Bayliss, P., & Gillespie, S. (2019). Developing family-centred care in a neonatal intensive care unit: An action research study. *Intensive & Critical Care Nursing, 50,* 54-62. doi:10.1016/j.iccn.2018.05.006

Smith, B. J., Tang, K. C., & Nutbeam, D. (2006). WHO health promotion glossary: New terms. *Health Promotion International, 21*(4), 340-345.

Spinelli, M., Frigerio, A., Montali, L., Fasolo, M., Spada, M. S., & Mangili, G. (2016). "I still have difficulties feeling like a mother": The transition to motherhood of preterm infants mothers. *Psychology & Health, 31*(2), 184-204. doi:10.1080/08870446.2015.1088015

Stanley, M., & Nayar, S. (2014). Methodological rigour: Ensuring quality in occupational therapy qualitative research. *New Zealand Journal of Occupational Therapy, 61*(1), 6-12.

Tashakkori, A., & Teddlie, C. (2010). *Handbook on mixed methods in the behavioral and social sciences*. Sage Publications.

Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Sage Publications, Inc.

Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved, 9*, 117-124.

Townsend, E., & Wilcock, A. A. (2004). Occupational justice and client-centered practice: A dialogue in progress. *Canadian Journal of Occupational Therapy, 71*(2), 75-87.

United States Census Bureau. (2018). *Quick facts*. https://www.census.gov/quickfacts/fact/table/atlantacitygeorgia,US

VanderKaay, S. (2016). Mothers of children with food allergy: A discourse analysis of occupational identities. *Journal of Occupational Science, 23*(2), 217-233. doi:10.1080/14427591.2015.1119713

Vergara, E., & Bigsby, R. (2004). *Developmental and therapeutic interventions in the NICU*. Paul H. Brooks Publishing Company.

Ward, K. (2001). Practice applications of research. Perceived needs of parents of critically ill infants in a neonatal intensive care unit (NICU). *Pediatric Nursing, 27*(3), 281-286.

Widding, U., & Farooqi, A. (2016). “I thought he was ugly”: Mothers of extremely premature children narrate their experiences as troubled subjects. *Feminism & Psychology, 26*(2), 153-169. doi:10.1177/0959353516636149

Wigert, H., Berg, M., & Hellström, A. (2010). Parental presence when their child is in neonatal intensive care. *Scandinavian Journal of Caring Sciences, 24*(1), 139-146. doi:10.1111/j.1471-6712.2009.00697.x

Wilcock, A. (1993). A theory of the human need for occupation. *Journal of Occupational Science, 1*(1), 17-24.

Wilcock, A. A. (2006). *An occupational perspective of health*. Slack Incorporated.

Wilcock, A. A., & Hocking, C. (2015). *An occupational perspective of health* (3rd ed.). Slack, Inc.

Winston, K. A., Dunbar, S. B., Reed, C. N., & Francis-Connolly, E. (2010). Mothering occupations when parenting children with feeding concerns: A mixed methods study. *Canadian Journal of Occupational Therapy, 77*(3), 181-189.

Woodward, L. J., Bora, S., Clark, C. A., Montgomery-Honger, A., Pritchard, V. E., Spencer, C., & Austin, N. C. (2014). Very preterm birth: Maternal experiences of the neonatal intensive care environment. *Journal of Perinatology, 34*(7), 555-561. doi:10.1038/jp.2014.43

World Health Organization. (2018). *Preterm birth*. https://www.who.int/news-room/fact-sheets/detail/preterm-birth#targetText=Preterm%20is%20defined%20as%20babies,preterm%20(less%20than%2028%20weeks)&targetText=moderate%20to%20late%20preterm%20(32%20to%2037%20weeks).

Appendix A

Initial Interview Questions

1. Tell me about your pregnancy and delivery experience.
2. What were your initial thoughts when you learned your baby would be admitted to a NICU?
3. Tell me about your experience of having a premature infant admitted to the NICU.
4. Tell me about a typical day for you and your baby in the NICU.
5. Describe your experience with caring for your premature infant while in the NICU.
6. Tell me about what the medical staff has done to prepare you for caring for your baby.
7. Tell me about how the NICU and hospital environment has supported or hindered your ability to care for your baby.

Appendix B

Follow-up Interview Questions

1. Is there anything you would like to further discuss regarding your experience of having a premature infant in the NICU now that you have had some time to think since your first interview?
2. Describe your experience of working with therapy services, such as occupational therapy and/or physical therapy.
3. What piece of advice would you give other mothers new to the NICU?
4. Is there anything you would like to share with me that we haven't discussed?

Appendix C

Institutional Review Board Approval

APPROVAL

February 5, 2020

Jennifer Nelson, MOT, OTR/L, BCP, CNT
Dear Dr. Nelson:

On 2/5/2020, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title:	What is the lived experience of mothers of premature infants in a level IV NICU?
Investigator:	Jennifer Nelson, MOT, OTR/L, BCP, CNT
IRB Number:	STUDY00000491
Funding:	None
Grant Title:	None
Grant ID:	None
IND, IDE, or HDE:	None
Documents Reviewed:	• Appendix A, Category: Questionnaires; • Appendix B, Category: Questionnaires; • Appendix B, Category: Questionnaires; • Appendix C, Category: Recruitment Materials; • Appendix D, Category: Questionnaires; • Department approval email, Category: Other Study Materials; • Dr. Piazza's approval email, Category: Other Study Materials; • informed consent NICU mothers 2-5-20 CLEAN.pdf, Category: Consent Form; • protocol NICU mothers 2-5-20 JN CLEAN.docx, Category: IRB Protocol;

The IRB approved the protocol from 2/5/2020.

Attached are stamped approved consent documents. Use copies of these documents to document consent.

Submission ID: STUDY00000491
Date Approved: 2/5/2020
Date Expiration:

Institutional Review Board approved the above referenced study.

☒ The stamped approved informed consent document for use in this study is attached. Only this original shall be used to make copies for study enrollment. You may not use any informed consent document that does not have this Institutional Review Board's current stamp of approval. The board has determined one parent signature is required.

☐ The requirement for written informed consent, parental permission and assent is waived for this study and an alteration of HIPAA Authorization has been granted. The IRB has determined that all specified criteria described in 45 CFR 46.117(c) and 45 CFR 164.512(i)(2)(ii) has been met as necessary to obtain a waiver of documentation of informed consent, parental permission and an alteration of HIPAA authorization.

☐ The requirement for informed consent, parental permission and assent is waived for this study. The IRB has determined that all specified criteria described in 45 CFR 46.116(d) has been met as necessary to obtain a waiver.

☐ The requirement for authorization for the release of protected health information for research purposes is waived for this study. The IRB has determined that all specified criteria in 45 CFR 164.512 has been met as necessary to obtain a waiver of HIPAA Authorization.

☒ The requirement for HIPAA authorization of release of protected health information is partially waived for this study.

☐ This study is open for data analysis only.

In conducting this protocol, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

Sincerely,
Office of the IRB

Submission ID: STUDY00000491
Date Approved: 2/5/2020
Date Expiration: