THE LONELY BATTLE: WOMEN’S JOURNEY THROUGH THE NICU

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THE LONELY BATTLE: WOMEN’S JOURNEY THROUGH THE NICU

By

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Dissertation

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in Counselor Education and Supervision

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One in ten pregnancies end with placement of an infant into the NICU (NCHS, 2021). NICU mothers experience increased rates of PTSD, anxiety, and depression, (Lefkowitz et al., 2010; Lotterman et al., 2019) and little is known about their lived experiences in the NICU. To gain a better understanding of the stressor’s women face, this research asked: How do women with infants in NICU care make meaning of their NICU experience? Using Interpretive Phenomenological Analysis (Smith et al., 2009), two rounds of semi-structured interviews were conducted with six participants. The results revealed women’s emotional experiences while having an infant in the NICU. In this process, women move from sudden entry into the NICU to encountering challenges of being bypassed once there. Then, women manage their emotional energy with an external focus of *doing*, and later, in an internal, lonely, emotional battle. In this Deep Dark Battle, Women struggled with guilt, a sense of failure, and personal despair. Women also found supports to help them escape this internal spiral. Post-discharge, women worked to integrate their NICU experiences, often while managing pervasive anxiety and trauma. Women were also able to reflect on their strength and resilience after leaving the NICU. The findings establish the pain and distress women endure alone in the NICU. Results provide insight for offering accessible, skilled, counseling support and a position for medical providers to intervene with preventative care for women with infants in the NICU.
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Chapter I: Introduction

Each year 518,000 infants are admitted into the Neonatal Intensive Care Unit (NICU) in the United States. This means that nearly 1 in every 10 infants and the families that care for them will receive NICU care (World Health Organization, 2018). Infants enter the NICU for a multitude of reasons, including premature birth, intrauterine growth restriction (IUGR), low or very low birthweight, risk to the mom, substance abuse, and critical illness. Admittance may be planned or emergent, and in either case parents experience a deviation from the expected plans (Goutadier et al., 2011; Greene et al., 2015; Woodward et al., 2014). Having an infant admitted to the NICU can have negative impacts for mothers. Within the first year of a NICU infant’s life, at least 30% of their parents are likely to experience mental health challenges or receive a mental health diagnosis (Hynan, Mounts, & Vanderbilt, 2013). Further, Lotterman, Lorenz, and Bonanno (2019) conducted a longitudinal study on the psychological experiences in the NICU which reports mothers experience emotional distress, anxiety, depression and post-traumatic stress disorder at rates of 33.7% at admittance and 38.2% 6 months follow-up. For comparison, rates of Postpartum Depression (PPD) in mothers of healthy infants are reported between 9-13% (Bauman et al., 2020) rates of anxiety at 7.4-8.7% (Matthey, 2003), and rates of PTSD around 2.3-6% (Lefkowitz, Baxt & Evans, 2010). Rates of these mental health challenges continued to remain higher in NICU mothers even 6 months after birth (Lotterman et al., 2019). These long-term mental health outcomes indicate the intensity and complexity of women’s experiences associated with having an infant in the NICU. During a time when mothers would normally be greeting their newborn infant with feedings and holding, NICU mothers are instead navigating a multitude of novelties and uncertainties while addressing the health and survival of their newborn. Simultaneous to their parenting experience, women are also navigating their own
personal processes. The many aspects that make up a woman will undoubtedly be impacted by the experience of having an infant hospitalized in the NICU. The current literature focuses on how parenting is impacted or about the experiences of becoming a mother in the NICU (Gibbs et al., 2015; Krick et al., 2021; Lasiuk et al., 2013; Obeidat et al., 2009; O’Donovan & Nixon, 2019). The personal experiences of the mothers and the aspects of themselves beyond the role of mother have yet to be explored in depth. This study will aim to gain a broader and deeper perspective of the woman, who is one part a mother. Aspects to consider may be spiritual beliefs, her relationships, her career, her internal emotional experiences, and other identities that are likely influenced by the critical incident of NICU stay. This study explored the experiences of women who deliver infants that require NICU care. The aim of the study was to understand the many aspects and layered identity of the mother and expanding our understanding of her experience beyond caregiving. By learning more of the experiences a woman faces while having an infant hospitalized in the NICU, there was also room to explore ways she made meaning of these experiences. With increased perspective of how women make meaning of their NICU experiences, we may better understand possibilities for increasing support for this population.

The role of gender and parenting is complex and multilayered. For this study I chose to specifically explore the experiences of women who give birth to infants requiring NICU care. When referencing the design of this study, I refer to women and mothers. When reviewing the literature, the terminology about parenting in the NICU is vast and often interchanges terms of parents, mothers, and fathers. When reviewing the literature, I used language consistent with each respective study to maintain intentions of the authors.

**NICU Care**
Intensive care of newborns has developed and changed throughout the years. Research has examined and identified the ways that the infant-maternal dyad has been impacted by separation (Ionio & Di Blasio, 2014; Nystrom & Axelsson, 2002) and gained insight into ways to progressively support development of premature infants (Als, 2009). Recommendations for care for infants and their families have morphed and changed with these discoveries. The progression of care has moved from separation of the mother infant-dyad (Gooding et al., 2011) to addressing the family system as the patient by implementing Family Centered Care (FCC). By the early 2000s NICU care expanded to include Newborn Individualized Developmental Care and Assessment Program (NIDCAP), a developmental care standard that in its optimal form incorporates FCC (Als, 2009). Even as care has progressed to be family inclusive and considerate of attachment and infant development, gaps remain in the understanding of how the mother is holistically impacted by having an infant in the NICU.

**Historically removed/separated**

For many years medical care in the NICU across the United States, has concentrated solely on the infant as patient. This concentration led to separation between the mother and infant while the infant was in the care of the hospital staff (Gooding et al., 2011). With this orientation, common practice was to remove the infant immediately from the mom, place them in a warming bed (isolette), and require the parents to return only for discharge (Gooding et al., 2011; Nystrom & Axelsson, 2002). This separation has created known damage to both the parent-child bond and the neurodevelopment of the child (Field, 2010; Nystrom & Axelsson, 2002; Steinberg & Patterson, 2017).

As the medical care of neonates progressed there have been many efforts to move away from separating mother and baby (Gooding et al., 2011). However, depending on the severity of
illness, immediate separation may be necessary for infants to receive emergency or required care. NICU mothers report a perceived loss of the parental role when separated from their infant (Woodward et al., 2014) despite knowing that this separation was due to medical necessity. Mothers may experience significant emotional distress and strain as parents, as well as challenges with the parent-infant bond when infants are removed from their care (Woodward et al., 2014). Although the Woodward et al., study gives insight into the mother’s experiences of perceived stress and the sense of loss regarding the parenting experience, it fails to examine the woman’s experiences through a holistic lens. The absence of understanding the many individual and specific experiences of the woman leaves a gap in understanding and holistically supporting her, and subsequently, her infant.

**Conventional Care**

The World Health Organization has addressed the need to increase maternal-infant bonding, ultimately decrease negative effects to infants, by recommending a reduction in separation between mother and baby in the NICU (WHO, 2003). In response, many hospitals which once engaged in separation as standard care, began to implement strategies to alleviate the barriers that may arise for both parents and the neurodevelopmental of the child (Gooding et al., 2011). With advancing medicine, and paradigm shifts towards collaborative care in the NICU, many efforts have resulted in increased opportunities for attachment with parental figures and for treating the family system of the infant (Steinberg & Patterson, 2017). Some of these new efforts include visitations by parents, skin-to-skin contact, opportunities for breastfeeding, and occasions to engage in caretaking of the infant (Craig et al., 2015).

**Family Centered Care**
In 1993, Helen Harrison introduced the concept of Family Centered Care (FCC) into the NICU. FCC is a holistic approach to care that acknowledges the patient within their family systems. FCC addresses and implements healthcare which considers familial needs and input. FCC proposes a collaboration between medical professionals and the family of the patient to create increasingly supportive care (Gooding et al., 2011). In FCC, medical professionals work to understand the experience of the family and then implement care that is inclusive and personalized to the family system. This approach creates the opportunity for family members to be actively engaged in the caretaking of their infant, identifies needs within the family and aims to support these needs, and empowers mothers and fathers to collaborate with medical staff regarding the wellbeing of their infant (Maria & Dasgupta, 2016). FCC follows four guiding principles which informs its practice:

1. Participation by the family in the infant’s care.
2. Respect for each patient and family member as an individual.
3. Collaboration and partnership when communicating with family.
4. Information sharing and education about medical care and processes.

These principles ultimately aim to increase the neurodevelopment, the physiological wellbeing of the infant, and support maternal-infant bonding (Maria & Dasgupta, 2016). FCC approach is emotionally supportive to mothers with infants in the NICU (Craig et al., 2015). Mothers who received and had positive experiences with family centered care were more engaged with the infant, expressed feeling more confident in their ability to care for their infant, held a greater desire to take active care of their baby, and had lower scores on stress assessments than mothers who did not receive this approach of care (Craig et al., 2015; O’Brien et al., 2013).
Despite continued requests for hospitals to adopt and integrate this approach into NICU settings, many have not done so (Gooding et al., 2011). A common barrier to implementing this practice is an incongruence among staff of how they perceive the necessity for FCC and their willingness to implement and change routines in the hospital setting (Peterson, Cohen & Parsons, 2004). Medical and nursing staff often express uncertainty about how to specifically implement this approach due to FCC’s broad and vague concepts. When combined with lack of education and training, implementation becomes an even bigger task (Coyne, 2015). Families also have uncertainty about the FCC approach and may be unwilling to be involved in care for the infant (Coyne, 2015). Finally, FCC moves away from the hierarchical approach to medicine in which the doctor makes all medical decisions alone. Though this has appeal to family members, it may leave physicians hesitant to adopt this new approach (Maria & Dasgupta, 2016).

For those hospitals that have embraced FCC as a care approach, they have developed ways to incorporate occasions for parents to be actively involved in the care of the infant. Kangaroo care, the skin-to-skin holds which promotes positive attachment and bonding between mother and baby (Feldman et al., 2002) is one such method. Other mechanisms for implementation of FCC practice include parent education, peer support groups, design of the NICU to offer private rooms for visitation, and opportunities for breastfeeding. In FCC parents are encouraged to be present for doctor’s rounds, and also engage in providing care to their infant. They are given information, and the meaning of the information about their infant and encouraged to add their input when exchanging information.

**Opportunity for Kangaroo Care.** FCC has developed practices which support maternal-infant bonding, infant wellness and maternal engagement. Kangaroo Care (KC) is a Skin-to-skin contact practice that is often addressed in hospitals implementing FCC. Kangaroo Care is a
practice developed by Dr. Edgar Rey in 1978 and later implemented in the United States NICU settings with premature infants. Kangaroo Care facilitates skin-to-skin contact between parent and infant, largely conducted by placing the mostly naked baby on the breast of the mother in a kangaroo like position (Tessier et al., 1998). Kangaroo Care has been shown to be helpful in increasing the parent-child bond, and decreasing the parents’ sense of loss of their role as the caregiver (Feldman et al., 2002). Mothers implementing Kangaroo Care with their NICU infants reported increased senses of competence with their babies (Steingberg & Patterson, 2017; Tessier et al., 1998). Further, mothers who engaged in skin-to-skin holding reported a sense of learning and getting to know their infant, indicating connection to their infant (Gale, Franck & Lund., 1993). Per WHO recommendations, this attachment building practice begins after the infant is stabilized. Often this initial contact begins within 3-7 days, though the hope is for implementation as soon as is possible after birth (WHO, 2019).

**Visitation.** In the FCC approach parents are offered limited times to visit their infants in the NICU. Parents are encouraged to attend their visiting schedules and encouraged to remain for the duration of the visit. During this time, parents engage in active care of their infants by changing diapers, weighing the infant, holding and feeding the infant; however, all these activities require the infant to be hemodynamically stable. Parents are encouraged to be present for doctor rounds or talk with the NICU physicians on a daily basis to review infant progress and medical staff to review daily changes and developments regarding their infant (Russell et al., 2014).

As FCC continues to gain support in the United States there continues to be opportunities for further development of the goals of family wellness and support. One of the goals of FCC is to address the needs of the infant as the patient, as well as their family members. The aim of FCC
is to increase quality of care for both the patient and the family (Coyne, 2015; Gooding et al., 2011).

Although FCC models successfully integrate family involvement in the care process, when it comes to caring for mothers, research has failed to examine her holistic experience in the NICU and little is empirically known about supporting her outside her role as mother. If women’s internal and personal experiences are left unvoiced and not understood, the gap for increasing quality of life in this family member is a potentially unmet goal of FCC. By developing better understanding of the woman’s holistic experiences, we can better attend to the mother’s overall wellness with direct counseling and medical support. This increased support to the woman, could also in-turn increase quality of life for the entire family system.

**Developmental Care**

Some NICU’s use a Developmental care model which focuses on supporting the developmental and emotional needs of neonates. This approach aims to individualize infant care to maximize the neurological development of the infant. Implemented in early 2000s, this approach works to decrease stress to the infant and creates a controlled environment that is as much like the intrauterine environment as possible. Infants born before 37 weeks are not physically or developmentally mature enough to transition to the environment outside of the mother’s uterus. They are unable to control basic body regulations such as temperature control, breathing, and blood pressure. Often because of this, infants are unable to maintain weight or stable vital signs. All of these consequences can lead to long-term neurological consequences for the infant, if not treated in a controlled environment (Als, 2009). In developmental care models, the infant is placed is conditions which mimic intrauterine conditions such as having a dark, quiet, and temperature-controlled environment. Stimulation to the infant including lights,
sounds, and touch are minimal. The goal of developmental care models is to decrease stress to the infant while optimizing individualized care towards the infant’s full-term development (Byers, 2003).

**Environmental changes.** NICU rooms may either be open bay or single rooms. Open bay rooms are larger rooms which may have pods of 8-10 babies with separation by curtains. Single rooms provide greater opportunity for privacy and family intimacy. NICU rooms with a developmental care approach work to control lighting by having the lights either off or dimmed most all of the time. Noise levels are controlled by limiting visitors and encouraging a quiet space. Room temperatures are controlled to mimic the womb and isolettes and warming beds are used to help infants keep their internal temperatures constant and up, so caloric expenditure is limited (Byers, 2003; Craig et al., 2015).

**Cluster care.** Unless emergent, all routine care is completed in specific times during the day, most often prior to scheduled holds by family members. This includes blood pressures, intravenous (IV) blood draws, daily weigh-ins, changing, breathing apparatus changing/cleaning, and feedings. This model allows mothers and fathers to be involved in caring for their infants by active engagement in changings and feedings that happen after medical care is offered. After participating in the cluster care process, mothers will have their scheduled holds with their infant.

**Holding schedules.** Visitations between parent and baby are scheduled to several holds per day, depending on the health of the infant. Implementation of scheduled holds addresses both maternal-infant bonding while simultaneously remaining aware of the infant’s need to continue developing in an environment that does not have extra stimulation for the infant. When holdings are scheduled, parents must adhere strictly to the schedule to avoid disrupting infant sleep.
Should holding not be possible due to medical fragility or complexity, mothers may use this time to touch their baby through the isolette windows (Byers, 2003).

Developmental care is a model which integrates specialized care to support the premature infant in continued growth and neurological development. It offers specific changes to the NICU environment including holding schedules, dimmed lights, specific visitation, decreased noise levels, and cluster care in order to decrease the amount of stress to the infant. In hospitals which use a developmental approach have varying degrees of implementation. The optimal form of developmental care is Newborn Individualized Developmental Care and Assessment Program (NIDCAP), which integrates both FCC and Developmental care practices (Als & Mcnulty, 2011).

**NIDCAP**

In 1984 Heidelise Als introduced the concept of NIDCAP to NICU care. The aim of NIDCAP is to offer optimal care to both infants requiring NICU care and their families. NIDCAP is a relationship-based intervention model aiming to address the improvement of relationships for infants, families and medical staff caring for the infant (Als, 2009). It uses the observation of the infant’s behavioral functioning along with the physical and social environment to inform medical staff about the needs of the infant and ultimately decrease complications to the infant’s health. NIDCAP derives from the belief that the infant, the family’s needs and desires, and the staff involved with the infant will all interact and have influence upon the health of the infant. NIDCAP care is adapted to each individual accordingly with the ultimate desire to enhance developmental outcomes of the infant (Als et al., 2003; Als, 2009).
Though developed and introduced in 1984, the integration of this approach into hospitals did not truly begin until the early 2000s as the commitment to integration of this model requires both growth and change by medical providers and to the greater hospital system (Als, 2009). NIDCAP is the essence of optimal developmental care, and as such integrates FCC into the model, allowing the family to be involved in decision making, gain information about their infant, and offering education to parents and staff within the NICU setting (Als & Gilkerson, 1997). The outcomes of developmental care have shown to be positive for infants as well as parents (Als et al., 2003). In a randomized controlled study, three US NICU’s parental stress two weeks after the original due date of their infant was less than when compared with the control group not receiving developmental care (Als et al., 2003). Mothers of infants receiving developmental care also perceived having more connection to their infant, and increased satisfaction with parenting to infants than mothers whose infant did not receive developmental care (Kleberg et al., 2006; Johnson, 2007).

The progression of care in the NICU reflects profound movement from separation to family consideration and integration. With increasing information about infant wellness and parental attachment, medicine has moved to alleviate negative consequences of separation for both infant and parents. However, despite all the growth and advancement made with regards to parenting in the NICU, there continues to be a lack of exploration of what women experience holistically while having an infant in the NICU. Without knowing this full experience of the woman there remains a gap in understanding how women are impacted and affected personally, beyond their mothering role. By further understanding the holistic experience of women who are mothers in the NICU, there is possibility for increased opportunities to support the wellbeing of these women.
Parenting in the NICU

Mothers and fathers face challenges when parenting an infant in the NICU. Care is often invasive and laden with both physical and emotional challenges (Holditch-Davis et al., 2003). Parents also face unique challenges with attachment and both uncertainty and the loss of their parenting role (Krick et al., 2021; Obeidat et al., 2009). Finally, due to the physical and environmental barriers associated with parenting a NICU infant, parents also experience questioning of self, and difficulty with their ability to parent their infant (Heerman et al., 2005; O’Donovan & Nixon, 2019; Turner et al., 2015).

Obstacles to parenting

Upon their infant entering the NICU, mothers face unique challenges and obstacles to parenting. One such challenge can include invasive care which prevents mothers from having open access to their infants (Lefkowitz et al., 2010). Combined with difficulties being able to freely touch and hold their infants, NICU mothers are adjusting to daily, sometimes even hourly, changes and nonlinear progression of the infant’s health (Obeidat et al., 2009). Mothers experience questioning their role as a parent, questioning their competency as a parent, (Lasiuk et al., 2013) and a loss of control and difficulty with attachment to their baby (Craig et al., 2015).

Invasive care. Whatever the reason for entering the NICU, an infant’s entry indicates a need for a higher level of care than a standard labor and delivery or postpartum nursing unit can offer. The need for NICU care often requires intense invasive care that brings challenges and difficulties for the baby and parents alike. Though not an exhaustive list, common reasons for admittance to the NICU include premature birth (before 37 weeks), respiratory distress, infection or illness of the infant, and exposure to substances in utero (WHO, 2019). Parents may be present during traumatic medical events including coding and resuscitations, sounding alarms,
and sudden medical intervention (Maroney, 1994; Obeidat et al., 2009). Simultaneously, the level of care often required in the NICU can be alarming and distressing to parents. Parents may see their newborn constantly monitored for dropping or changing vitals, experience a multitude of internal images and tests, and, at times, rely on life-sustaining medical supports (Holditch-Davis et al., 2003). These occurrences can add to the parents’ experience of distress and trauma. Instead of welcoming their newborn in peace, parents are faced with immediate concern regarding the wellbeing of their infant and instead are focused on learning medical teams, medical terms, new routines, navigating physical and emotional obstacles, and often focusing on the survival of their infant (Holditch-Davis et al., 2003; Nystrom & Axelsson, 2002). Invasive care impacts parents in numerous ways. Parents may experience fear of not knowing what is to come and intense fear of death or long-term consequences to their infant. Another consequence to parents with infants receiving invasive care is the constant reminder of how fragile and ill their infant is (Clottey & Dillard, 2013).

**Environmental challenges.** The NICU environment itself carries numerous factors that influence parenting. Maroney (1994) discusses the ways that NICU parents’ senses are often overstimulated and saturated by input that is both new to the mother and pervasive. This input comes from a variety of external factors including sounding alarms, specific and strong odors, medical language, and multiple visits per day by different visits by multiple members of the health care team including nurses, physicians and therapists. These environmental challenges can increase the distress and strain that parents are living with during this already intense time (Holditch-Davis et al., 2003).

**Physical barriers.** Mothers of NICU infants are often faced with physical barriers to providing care. Initial holdings are often replaced by introductions to their baby through the glass
of an isolette, sometimes with multiple apparatuses crowding their faces and bodies. Due to the severity of medical complications and life sustaining support, mothers may not be offered the opportunity to hold their infant until days or even weeks after their infants’ birth (Craig et al., 2015). When given the opportunity to hold their infant, mothers may have to navigate multiple wires, isolettes, feeding tubes, IVs, breathing apparatuses, and other medical devices attached to the infant. These interventions create physical boundaries interrupting the expected experiences of greeting a newborn (Lotterman et al., 2019). These physical obstructions create obstacles and experiences of fear of completing basic parenting tasks such as changing, touching, and feeding infants (Gibbs, Boshoff, & Lane 2010).

**Attachment Challenges**

Separation of baby and mother can create challenges with the mother-infant dyad’s initial attachment (Baylis et al., 2014; Nystrom & Axelsson, 2002). Mother-infant attachment is the development of emotional bonds between the baby and mother. This attachment is developed through the early years of life, beginning during pregnancy and further strengthened by mother-infant bonding after birth (Ainsworth, 1979; de Cock et al., 2016). The internal working model developed in these early years informs of how individuals may engage in relationships with others (Ainsworth, 1979). Maternal-infant bonding, related to attachment, is the experience of maternal affection and engagement towards the infant after birth (Feldman & Eidelman, 2007; Forcada-Geux et al., 2006). This bonding, developed by physical contact, scent, and gaze can lead to connection between the mother-infant and/or father-infant dyad (Feldman & Eidelman, 2007). Results of positive bonding include developmental neurological and physiological benefits to baby and positive impacts for mother’s desire for engagement and care to the infant (Forcada-Geux et al., 2006).
When separated, mothers often experience a perceived lack of opportunity to care for their infant (Nystrom & Axelsson, 2002). These lost opportunities create a sense of emotional disconnect between the dyad (Craig, 2015). The disconnection may lead to the mother misunderstanding the infants’ cues and communication (Mylnek et al., 2006). This lack of engagement and awareness of their infants’ needs can lead to parents believing their infant is challenging and create further negative impacts to the parent-infant connection also leading to negative outcomes for the cognitive, social, emotional and behavioral functioning of the infant. (Craig et al., 2015; Miles-Holditch, 2003). NICU staff have worked to address and correct this parenting challenge via implementation of family centered care and developmental care approaches in the NICU setting. Practices such as Kangaroo Care, opportunities which allow mothers to provide care to their infant, scent interventions (a practice of passing a small cloth with mother’s scent on it between mother and baby), and breastfeeding are all interventions aimed at combatting the attachment difficulties NICU parents face (de Alencar et al., 2009; Anderson et al., 2003; Ferber & Makhoul, 2004). However, these challenges remain due to the complexity and uncertainty of medically fragile infants.

A study conducted by Fegran, Helseth and Fagemoen (2008) conveys that it is not merely the physical separation that can lead to attachment challenges between baby and mother. This hermeneutic qualitative study of 12 participants examined attachment experiences of six mothers and six fathers with their NICU infant. Though the main focus of the study was to compare mothers and fathers’ experiences, the results identified the mother’s emotional situation combined with the physical condition of her body after delivery may become a barrier to connection, and divert the mother-infant attachment. This gives insight to the way mothers as individuals are experiencing their own internal process, the effects on the infant bond, and
encourages continued research to further explore the emotional and physical experiences of mothers in depth. By doing so, there is opportunity to learn about the mother’s holistic experience. With increased understanding of the ways that women are impacted by this journey, there is opportunity to offer more thorough care to increase the wellbeing of the woman.

**Uncertainty and Loss**

Parents express a sense of loss of their role as caregiver when unable to offer their desired attention and comfort to their infants (Lasiuk et al. 2013). Parents may feel pushed aside in order for medical staff, nurses, and doctors to meet the medically complex infant needs (Nystrom & Axelsson, 2002). Nystrom and Axelsson (2002) interviewed eight women, using a phenomenological-hermeneutic approach, about their experiences of separation from their infant due to required NICU care. One theme which emerged from this study was of the mother feeling as an outsider to care and subsequent feelings of powerlessness and disappointment.

Lasiuk, Comeau and Newburn-Cook (2013) conducted an interpretative descriptive study examining 14 parents’ (11 mothers and 3 fathers) experiences of preterm birth of their infant. Participants included couples and individuals and used purposeful sampling to recruit participants from a Canadian city. Lasiuk, Comeau and Newburn-Cook interviewed healthcare providers who work with preterm infants and families. The data was collected both through interviews and focus groups. The study examined the trauma experiences of parents with preterm babies. Themes of helplessness, horror, fixation on the infant’s health, and ways to foster adaptation to the parenting role were persistent. With increased understanding of parental experiences of the preterm birth of their infant, medical staff and counseling fields gain opportunity to further support and provide appropriate care to help mitigate the trauma that parental caregivers are living through.
Lasiuk et al. (2013) study offers further insight into the ways in which parents experience a loss of dreams and plans about their child, the birth, and initial moments and days in the NICU. One example of the loss of plans at birth was highlighted from a mother who shared the distress and confusion she endured when her baby was taken into NICU care: “she wasn’t breathing very well, so they took her away, which was horrifying because, you know, you just have this baby and your intention is to hold it and bond with it afterwards and they take it away” (p. 4).

The Lasiuk et al. (2013) study further outlines the feelings of uncertainty and helplessness that parents may experience during a NICU hospitalization. Though the loss and difficulty are clear, we know very little about how mothers integrate, make meaning, or cope with such loss. Understanding more about the mother’s holistic experience extending beyond their parenting role may help care providers better support mothers as a whole-person, rather than solely from the mentality of woman as mother.

Gibbs, Boshoff, and Stanley (2015) also portray emotional loss of the expected plans when parenting preterm infants in the NICU. They conducted a meta-ethnographic synthesis in which they reviewed 35 qualitative articles which explored the parenting experiences in the NICU. Of the eight themes that emerged, several spoke to the experience of grief and loss. One theme was titled relinquishing the imagined role of parent. NICU mothers are grieving the loss of dreams of taking their infant home shortly after birth, nesting, napping, and rocking their baby to sleep. NICU parents are working intently on adjusting to the complexities before them and the immediate and basic needs of survival of their infant.

Parents also report experiencing uncertainty while having an infant in the NICU (Lasiuk et al., 2013). Uncertainty about their infant’s health, about the NICU process itself, and about the
future (Clottey & Dillard, 2013; Krick et al, 2021; Lasiuk et al., 2013). Results from the Lasiuk, Comeau and Newburn-Cook (2013) qualitative study also highlight uncertainty. They reported parents experienced uncertainty regarding their infant’s wellbeing and survival. This study also highlights parents’ ongoing uncertainty in the NICU, when even slight shifts occurred in the health of their infants. For parents in this study, the uncertainty remained high throughout the duration of their infant’s hospitalization.

Another grounded theory study of 24 former and current NICU parents identified a model of three phases of parental uncertainty (Krick et al., 2021). This study outlines the phases as 1. shock, 2. gray daze, and 3. looking forward. In the initial phase, parents reported their uncertainty about the ambiguity of their infant’s wellness and their own inability to look into the future regarding either the life of their infant or the future of their family. The second phase identified a lingering uncertainty in the midst of the hospitalization regarding continued treatment, timelines, and the infant’s progression. This phase was also marked by uncertainty regarding a continued lack of clarity for the family’s future. The final phase identified from this study was that of looking forward, in which parents identified beginning to accept uncertainty as a part of the experience of having an infant who required NICU care. Though uncertainty was still present in this stage, parents were able to integrate this uncertainty into their visions of the future (Krick et al., 2021).

**Competency and Self-efficacy Challenges**

NICU parents can experience a lack of opportunity to parent their infant, because of the infant’s medically complex needs. The role of the nursing and medical staff is necessary and prominent regarding caregiving for the infant (Heerman et al., 2005). Parents may experience a lack of readiness to engage in their new role of mother or father due to lack of engagement with
the infant because of how pronounced the nurse’s caregiving role is in the infant’s life (Lasiuk et al., 2013; Heerman et al., 2005). Heerman, Wilson, and Wilhelm (2005) examined the experiences of 15 women on becoming a mother while having an infant in the NICU. From the rich interviews they were able to outline a maternal role development continuum. Heerman, Wilson, and Wilhelm do not specify their particular methodology or the questions they used in the interview to support development of the continuum. The results from the study found themes of mothers moving from a passive role to an active role over the course of their infant’s stay. They highlight mothers’ feelings of inadequacy about knowing how to care for their infant, fear of the fragility of their infant, and concerns of their own ability to correctly care for their ill infant.

Though many studies examine the experiences of parenting in the NICU, the literature is lacking in examination of the in-depth exploration of the mother’s personal experiences. Though understanding the parenting role is necessary, it does not eliminate the need to better understand a holistic individual experience to better support both the individual and their system.

**Mother Mental Health Outcomes**

The mental health outcomes of mothers parenting in the NICU have been well-documented - rates of post-partum depression (PPD), post-partum anxiety (PPA), acute stress disorder (ASD), and posttraumatic stress disorder (PTSD) are all found to be higher in NICU parents than in those whose infant was born healthy and at term (Clotey & Dillard, 2013; Lefkowitz et al., 2010; Obediat et al., 2009; Rogers et al., 2013; Turner et al., 2015). These outcomes give us insight into the intense challenges that mothers are facing. Further understanding of how mothers are arriving at these diagnoses and increased symptom rates
deserves to be explored. A closer examination of the individual and whole woman may begin to provide insight about her experiences and potentially these outcomes.

**Anxiety**

Mothers whose infant is in the NICU, predictably experience anxiety (Obediat et al., 2009). One study found that 24.7% of mothers during hospitalization met criteria for clinical anxiety and 27.6% of mothers met the criteria for PPA 6 months later (Lotterman et al., 2019). Comparatively, 7-8% of mothers with healthy infants experience clinical anxiety (Matthey et al., 2003).

Rogers, Kidokoro, Wallendorf, and Inder. (2013), examined 73 mother-infant dyads in a quantitative study addressing both anxiety and depression rates in mothers with infants in the NICU. The State Trait Anxiety Index (STAI) assessment was used to examine mothers’ levels of anxiety at discharge. The STAI is often used to assess state anxiety with caregivers (Greene et al., 2017). The results of this study identified 43% of participants scores indicated experiences moderate to severe anxiety. Scores at discharge were similar to the levels reported early on in the NICU stay. This identifies the intense anxiety that mothers are experiencing not only initially in NICU experiences, but at discharge as well.

Mothers articulated experiencing anxiety for many reasons. Mothers expressed anxiety about their infant’s well-being and the uncertainty of their infant’s health on a daily basis. (Jackson, Ternestedt & Schollin, 2003). They also reported experiencing anxiety about medical interventions and equipment being used, as well as questioning their ability to care for their ill infant. Mothers also identified experiences of anxiety as discharge approaches. Even after being home, mothers discussed worry and distress about the possibility of their infant being re-hospitalized due to reoccurring illness and having a high-risk infant (Turner et al., 2015).
Acute Stress Disorder & Post Traumatic Stress Disorder

Parents may develop Acute Stress Disorder as they navigate the NICU with their critically ill infants. Symptoms of ASD, and in some cases Post Traumatic Stress Disorder (PTSD), are higher in NICU mothers than in mothers of healthy infants (Clotey & Dillard, 2013; Lasiuk et al., 2013; Lefkowitz, Baxt & Evans, 2010).

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5-TR; American Psychiatric Association [APA], 2022) defines ASD as the development of distinguishing symptoms lasting from three days to one month following exposure to a traumatic event. Traumatic events are defined as exposure to, or threat of serious injury, death, or sexual violation. To meet criteria for this diagnosis one must directly experience the event, witness the event, or learn of the event occurring to one’s child or close relative or friend. One example in the DSM-5-TR of witnessing the event is identified as ‘medical catastrophe during the course of their child’s illness or ongoing treatment’. NICU moms meet this definition due the frequent possibility of perceived catastrophe and potential threat to their infant’s life. This threat may be in the initial stages of hospitalization, or may be ongoing throughout the hospitalization (Clotey & Dillard, 2013). ASD has many overlapping symptoms with PTSD. Both PTSD and ASD diagnostic criteria include symptoms from five main categories: Intrusion symptoms, negative mood, dissociative symptoms, avoidance, and arousal. If nine symptoms from these categories listed in the DSM-5-TR are met, a diagnosis of ASD can be given. The difference between criteria in ASD versus PTSD is defined by the duration of the symptoms. ASD is likely to resolve within one month after the exposure of the threat whereas a diagnosis of PTSD may not be given until symptoms are lasting longer than one month (APA, 2022).
PTSD rates of parents in the NICU were noted by another study to be as high as 15% in mothers and 8% of fathers (Lefkowitz et al., 2010). Holditch-Davis, Bartlett, Blickman and Miles (2003) outlined that of 30 mothers who participated in the study, all 30 of the mothers had at least 1 symptom of trauma, and as many as 16 mothers had 3 or more symptoms. Within these high rates, 26 and 24 of the mothers from this study also reported arousal and re-experiencing and symptoms of avoidance, respectively. Again, these high rates indicate the level of suffering mothers are enduring while having an infant in the NICU.

The frequency of ASD and PTSD in NICU parents have been so high that Clottey and Dillard (2013) defined the concept of NICU induced-PTSD. NICU induced-PTSD parallels the symptoms of PTSD including intrusive thoughts, avoidance, arousal and re-experiencing (APA, 2022). Clottey and Dillard (2013) discuss that NICU induced-PTSD is influenced by factors such as possible trauma of preterm birth experience, an intense fear of the death of their infant, and fear of quality of life of the infant. They consider how invasive medical interventions such as dropping oxygen saturation, alarms, coding, resuscitations, and urgent care after delivery can contribute to factors of NICU-PTSD. Further, future doctors, alarms reminiscent of the NICU, hospitals, due dates, and specific smells may all also become triggers, inducing panic and anxiety.

**Depression**

Post-partum depression (PPD) is not uncommon in parents. Mothers who experience PPD have difficulty attuning and connecting emotionally and physically with their infants. They make less visual contact with their infants, are less affectionate, and have fewer vocal interactions and touch with their infants (Field, 2010). Although symptoms between PPD and clinical depression are the same, the difference between the two is based on time of onset and
number of symptoms present. Clinical depression is not related to pregnancy or childbirth where PPD’s onset is during pregnancy or in the four weeks following birth (DSM-5-TR, 2022). Though symptoms are the same, to receive a diagnosis of PPD (peripartum onset, as the DSM-5-TR (2022) refers to it), does not require that all criteria from Major Depressive Disorder (MDD) are met. The Center for Disease Control (2016) reported that about 13% of women experience PPD in the first year after the birth of a baby. Rates of PPD are higher for NICU parents in comparison to those with healthy newborns. One study done by Helle and colleagues (2015) identified NICU mothers at risk of developing PPD at 4-18 times the rate of those with healthy infants. Similar data show 39% of mothers with infants in the NICU reporting clinical levels of depression (Lefkowitz et al., 2010). In addition, NICU mothers experience subclinical levels of depression at higher rates than parents of healthy newborns (Beck et al., 2003; Lefkowitz et al., 2010). That is, although they may not meet diagnostic criteria for clinical depression, they are experiencing more than 2 symptoms of depression (depressed mood most days, diminished interest and pleasure in activities, weight loss/gain or increase/decrease in appetite, insomnia or hypersomnia, fatigue and loss of energy, feelings of hopelessness or worthlessness, decreased ability to think or concentrate daily, recurrent thoughts of death or suicidal ideation).

Further, rates of suicidal thoughts are higher for NICU mothers. Lefkowitz, Baxt, and Evans (2010) found that 33% of NICU mothers experience thoughts of suicide during their infant’s stay in the NICU. This is an alarmingly high rate of mothers who are reporting such intense thoughts. A longitudinal exploration of PDD and PTSD in parents indicated that symptoms did not decrease upon discharge, and remained even 6 months after their infants stay in the NICU (Lotterman et al., 2019). These findings expose the reality of long-term effects that having an infant in the NICU can present. From a methodological standpoint, these statistics
reveal a dearth of research that help us understand the lived experiences of women navigating the NICU. Learning about the holistic experiences that women are having while their infant is in the NICU offers opportunity for counseling support to address the experiences that may be leading to increased rates of mental health challenges in this population.

**Lived-Experiences of Mothers**

Beyond mental health outcomes and experiences with parenting, qualitative research has explored the lived experiences of parents’ perspective of NICU care. Russell et al., (2014) conducted a thematic analysis qualitative research study using a 12-question interview protocol to further understand the experiences of 32 mothers and seven fathers about the birth of their preterm baby and their satisfaction of care in the NICU. The methodological approach used in this study is not explicitly named. Using thematic analysis, three themes emerged to help inform parents’ experiences of preterm birth and parental satisfaction with care: parents’ involvement, staff competence and efficiency, and interpersonal relationships with staff all surfaced as ways that parents found satisfaction in NICU care setting.

Maternal experiences in the NICU have also been examined from a qualitative perspective. Turner, Hansen and Winefield (2015) implemented peer support groups for NICU mothers about their experiences of mothering in the NICU and how peer support influenced their experience. The methodology was a cross-sectional interview design using both a survey and interview to ask two direct questions: whether the participant would like more professional support, and whether they felt supported by their family. Thematic analysis of the nine interviews yielded themes that included; pregnancy and baby, with subthemes of guilt related to early term births, anxiety about possible death of the infant, and positive feelings about their infant. A second overall theme was parenting. The subthemes of this were anxiety about holding
baby and “letting go” as they returned the baby to the care of medical providers post-hold, and anxiety about being capable to take their infants home. A third theme found was titled Nurses. Subthemes of this were identified as parent-nurse relationship, and seeing midwives and nurses as positive influences on the nursery. The final overarching theme was Support. Subthemes of this were identified as support through education and information from professionals, sharing the emotional experience with others in a support group and finally, family support. The results of this study focus prominently on mothering and support specific to peer groups. Again, the exploration of a woman’s many identities, roles, and sense of self in addition to the mothering role has not been centered in the research.

Rossman et al., (2017) conducted a qualitative study examining the resilience factors in NICU mothers. The data from this study was pulled from a previous study examining maternal role attainment in the NICU. In the initial study, facilitators and barriers to maternal role-attainment with mothers of Very Low Birth Weight (VLBW) infants was examined and the gap regarding maternal resiliency factors was revealed. This led to the secondary analysis. Interviews of 23 mothers from the previous study were reviewed and analyzed using Narrative analysis and core story creation.

The findings of this study identified that for mothers, the experience of preterm birth and separation from their infant was traumatic. The authors go on to identify that mothers, despite the traumatic experience, were accepting of their new reality. Mothers worked to make meaning of their experiences by advocating for their infants. Results also discussed the “rollercoaster” experience of the NICU due to health challenges, medical procedures, and looming negative prognosis. Finally, support was a recurring resiliency theme throughout the narratives. This secondary analysis highlighted participants’ beliefs that support was critical to their mental
health and identified both the perceived presence, and absence of it. Participants identified a sense that their current friends and family did not understand what they were living through and thus, were unable to provide the support they hoped for. Participants of this study also identified peer support as incredibly helpful and offered encouragement for others to seek it out.

This study by Rossman et al. (2017) briefly begins to speak to other areas of women’s holistic experiences rather than solely from the perspective of mothering. This is seen in the explanation of the support theme and the way in which mothers identify difficulty with their friends and family during this trying experience. Although it touches briefly on this one area of the individual experience, the study does not progress further to examine or address the other holistic aspects and experiences outside themes of resilience.

O’Donovan and Nixon (2019) examined the experiences of mothers and fathers parenting in the NICU with preterm infants. Qualitative interviews were conducted with 13 participants (seven mothers and six fathers). Interpretive phenomenological analysis (IPA) was used to analyze the data. Four themes emerged from analysis of the data: addressing the traumatic experience of preterm birth, the experience of feeling disconnected, finding connection to the infant as a parent, and parents’ experiences of transitioning home. This study intimately examined and articulated the distressing and anxiety provoking experiences of parenting preterm babies in the NICU. One mother shared her intimate experience as: “I still loved him…. It just took a little while because he’d felt like he was being taken over by someone else.” The results of this detailed IPA study help counselors and medical providers to more deeply understand the mothering experiences that may be contributing to high rates of anxiety and depression for women. Yet, experiences beyond parenting do not receive inquiry. The holistic aspects of being a woman, who is one-part caregiver with an infant in the NICU do not receive breadth or depth.
A better understanding of women’s experiences navigating this significant incident, can expand our understanding of what she encounters and how to offer counselors and medical staff better insight regarding prevention and treatment of the mental health challenges this population faces.

**Psychological NICU Care**

In 2017 Steinberg and Patterson wrote a strong argument for integration of psychological care in the NICU. Grounded in review of previous literature the model they offer is a three-part model of relational NICU psychological interventions which includes: (1) the maternal/paternal experience, (2) transition to home, and (3) work with staff. Within these they different themes, case vignettes of mothers’ and fathers’ experiences of the NICU are highlighted. The authors use both quotes from mothers and fathers, and previous literature, to speak to the surprise and trauma of preterm birth, grief experiences in the NICU setting, and the experience of transitioning home. The third theme notes the importance to parents of relationships with the staff, and the ways that physicians and nurses can continue to offer support in their role.

Steinberg and Patterson’s (2017) persuasive piece argues for integration of psychologists into the NICU team for better emotional support to mothers and fathers throughout this experience. This article points to significant gaps in care of the mother and father individually, acknowledging themes of grief, loss, PPD, PPA, PTSD and the many emotional experiences that parents endure during a NICU stay. Although persuasive and valuable, and clearly grounded in previous literature, the article does not appear to come from a clear or transparent qualitative methodology. Thus, there is an opportunity for greater methodological clarity to gain a deeper understanding of women’s experiences on the NICU journey, and begin addressing the gap in mental health support for NICU mothers that Patterson and Steinberg so clearly argue for.

**Whole person perspective**
For much of history women’s roles have largely been defined as that of wife and mother (Dimmitt, 1994). During the 1900s it was not uncommon to hear public authority speak to the necessity of women as mothers, giving praise for housekeeping duties and the work of raising a family, while simultaneously demeaning the women choosing not to be married or birth children (Dimmit, 1994). This narrow view of women fails to address her as a whole person with differing needs, desires, and experiences. Expanding women’s identities as varied and multifaceted requires consciousness raising in order to attend to the many identities outside of the roles of mother and wife.

The medical treatment of postpartum women has also been deficient in further exploration or understanding of the woman beyond her role as mother. Though perinatal care to the woman and infant has been supported, the perspective of wellness for postpartum women is often infrequent and long overdue before women actually receive care (Tully, Stuebe & Verbiest, 2017). That said, the transition the woman experiences from non-mothering to mothering after the birth of their infant is filled with adaptation (Roy, 2013). She is healing from childbirth, learning to care for her infant, and adapting to physical, social, emotional and psychological changes (Aber, Weiss & Fawcett, 2013). Despite this awareness of major transition, and the many adaptations the woman is managing, little focus is placed on the experience of the woman holistically. The American College of Obstetricians and Gynecologists (ACOG, 2018) recently redefined the goals of postpartum care from previous recommendations. In their call for increased care they acknowledge the lack of follow-up and individualized holistic care specific to the woman (ACOG, 2018). The desire of ACOG’s redefinition to postpartum care is to optimize the health and wellbeing of both women and infants. The suggested approach is to
integrate care in the manner of ongoing, individual, holistic wellness of the woman (ACOG, 2018).

The ACOG task force calls for comprehensive postpartum care to include assessment of physical, social, and psychological wellbeing. Within these categories they identify mood, emotional wellbeing, feeding and care to infant, sexuality, sleep, fatigue, and physical recovery as some of the many aspects to be addressed.

Whole Person Wellness

For many years wellness was defined through the lens of the physical/medical perspective (Witmer & Sweeney, 1992). As the understanding of the concept of wellness progressed so too did the idea that the mind and body together comprise the individual (Swarbrick, 1997). This idea led to further development of a holistic approach to understanding of personal wellness. Today, models of whole person wellness include the many aspects of a person including spiritual, financial, physical, emotional, and social dimensions (Swarbrick, 2006).

As it becomes clear that postpartum women must be attended to more holistically, for the sake of their overall wellbeing, there is a need to identify what holistic wellness is, and the components which comprise wellness. Models such as the Indivisible Self (IS) and Wheel of Wellness (WoW) outline the many aspects of self that women with infants in the NICU may be navigating.

Wheel of Wellness (Wow)

Whole person wellness is the life orientation towards health and wellbeing in which the individual integrates body, mind and spirit (Myers, Sweeney & Witmer, 2000). The WoW is a model that addresses whole person wellness and characteristics of healthy functioning. This tool
was developed and later redefined to be used as a counseling intervention in supporting growth in the different aspects of the individual. Within the Wheel of wellness, there are 5 life tasks that the authors identify as components that make up the different aspects of a healthy individual.

- **Life Task 1: Spirituality** – The awareness of something greater than the material world, offering wholeness and connection to the universe.

- **Life Task 2: Self-Direction** – The way in which an individual intentionally directs self in the daily and long-term tasks and goals before them. Within this major life task, 12 subtasks were identified that make up parts of the whole person. These include: (a) sense of worth, (b) sense of control, (c) realistic beliefs, (d) emotional awareness and coping, (e) problem solving and creativity, (f) sense of humor, (g) nutrition, (h) exercise, (i) self-care, (j) stress management, (k) gender identity, and (l) cultural identity.

- **Life Task 3: Work and Leisure** – The opportunity for both pleasurable and challenging yet satisfying accomplishments.

- **Life Task 4: Friendship** – An individual’s social relationships involving connections who are not family.

- **Life Task 5: Love** – Relationships which are long-term and mutual and allow one to express and receive affection, to be intimate, trusting, and show their true self.

These tasks and subtasks are identified as the components of holistic wellness that can be addressed with individuals. Life tasks are informed and influenced by daily life forces including family, community, government and education and shift as the identity and experiences of an individual shift. This model was developed to be used in the counseling setting to begin examining the ways that an individual experiences wellness within each dimension of their life (Myers, Sweeney & Witmer, 2000).
Indivisible Self (IS)

Another variation of this model of wellness, the Indivisible Self (IS) is a strengths-based model of wellness. It was informed by the Adlerian concept of holism and purposiveness (Myers & Sweeney, 2004). In this model, a further adaptation of the WoW, both purposiveness and holism are developed as the first order factors of wellness. It again goes on further to defines 5 areas of wellness that comprise the whole person. The second order factors of this model include:

- Creative self: Individual attributes comprising social interactions, thinking, emotions, control, positive humor, and work.
- Coping self: Realistic beliefs, stress management, self-worth and leisure.
- Social self: Friendship and love.
- Physical Self: Exercise and nutrition.

Both of these models, as well as the dimensions offered by ACOG, present ideas about the many components of women that may have been neglected or unexplored after the birth of their infant. The postpartum woman with an infant in the NICU is navigating, simultaneously, her transition to motherhood, the many aspects of herself and her holistic wellness, all while also traversing the often traumatic and unconventional experiences of the NICU. In order to better attend to the holistic experiences of these woman we must learn and gain understanding of the aspects of self which are forgotten and unattended to as a result of the demands of their caregiver role.

Research has addressed motherhood, motherhood in the NICU, and even the experiences of preterm birth, yet the literature offers limited information, if any, about the holistic experiences
of women. In order for medical providers and counselors to better support women, it is necessary to know what is happening for the woman in the many parts of herself. Without clear understanding of the holistic experiences of the woman, it is unlikely for her needs to be met. This study is proposing we ask women, first hand, about their personal holistic experiences of having an infant in the NICU. The proposed study will seek to interview women who are 6-18 months post-discharge to allow for time to adjust to the maternal role at home, and to allow for women to have had healing space from the experience.

**Reflexivity of Researcher**

Qualitative research recognizes the researcher as an instrument in data collection and analysis. Given these roles, my reflections and experiences influenced this research. As a mother of an Intrauterine Growth Restricted (IUGR) baby, who was born at 31 weeks and at Very Low Birth Weight (VLBW), I was surprised by the sudden engagement in a long-term NICU stay. Upon entering the NICU I had little idea of what having my infant in a hospitalization would mean to both myself and my family. Our stay was 64 days, and full of ups and downs, disappointment, fear, guilt, worry, low oxygen saturations that lead to oxygen supplementation multiple times, and delays in getting our daughter home. All of this was frightening, exhausting, anxiety provoking, distressing, and after some time, expected. I had no preparation or support for the internal process I would find myself in while watching my infant struggle to survive and navigating this journey as her mother. I was engaged with multiple providers each day: doctors, physical therapists, occupational therapist, speech therapists, respiratory therapists, lactation consultants, and multiple nursing staff. Of course, these many visits were focused on the care of my daughter, and in their midst, there was no time nor anyone in the role to attend to my personal experiences or what would be truly supportive to me. Their lens was, and needed to be,
through that of my baby’s wellbeing and of me as a mother. It was through this experience that I became aware of the many intense experiences that occur by having an infant in the NICU. It was also this awareness and experience that lead me to begin to ask questions about how the mother as a whole person may be better understood and in turn, better supported by medical and nursing staff and with counseling support, rather than addressed solely as a mother. During this time, numerous NICU mothers sought me out to share their experiences. As word that I was a mental health counselor spread, mothers began reaching out and spending frequent time in our NICU room. They sought a place to quietly process and share their personal experiences of having their infant hospitalized. The magnitude of how many conversations I had with mothers seeking emotional support helped inform the need for counseling support to be offered in this environment. Before the argument for this additional support can be made, it is necessary to understand the experiences of these women. This need and the significant gaps in the research ultimately led to this study. As a result of this lived event in my own life, it was critical to maintain awareness around how my experiences inform and influence the design, collection, and analysis of data as I completed this study.

Summary

The experiences of mothers with infants in the NICU has been explored in great depth from a quantitative perspective. From this data it is clear that mothers, when their newborn child is in the NICU, experience an increase in mental health challenges and mental health symptoms. Concurrently, a lot is known about mothers’ experiences of parenting in the NICU. Qualitative studies have examined the experience specifically of preterm birth for parents (Lasiuk et al., 2013) and the experience of parenting an infant in the NICU (O’Donovan, et al., 2019; Turner et al., 2015). Though helpful in gaining understanding about being a mother and parenting, there
still remains a gap in the literature about what mothers who have an infant in the NICU are experiencing as individuals. Very little is known about the women’s internal and individual lived experiences. With soaring rates of PTSD, ASD, depression and even increased rates of suicidal ideation, understanding the lived experiences of mothers from a holistic perspective is critical. The hope of this study is to fill the gap in this research and give rise to the whole-person-perspective to the lived experiences of women with infants in the NICU. By gaining a deeper understanding of the lived experiences of this event there is opportunity to design better care for women.

This study sought to understand and explore the lived experiences and the many intersecting identities of the woman who has an infant in the NICU by way of qualitative phenomenology, specifically through the use of Interpretive phenomenological analysis (IPA). IPA is often used in examining specific events and moments in time through an in-depth layered analysis (Smith et al., 2009). In alignment with the IPA approach I asked the following research question: How do women with infants in NICU care make meaning of their NICU experience? This methodological approach is also often used in medical settings due the nature of its power to gather and examine detailed accounts of specific events. I conducted semi-structured interviews with six participants and continued with interviews to reach saturation. I analyzed the data with attention to the content of the interviews, from a linguistic perspective and conceptually. From this analysis themes were developed. I gathered participant reviews of the results as a form of member checking to ensure I accurately portrayed the voices of these women. Finally, after completing analysis and trustworthiness procedures, I shared the results of this lived experience with the women from this study.
Chapter II: Methodology

Introduction

Research indicates increased rates of mental health concerns among mothers with infants in the NICU. Mothers experience increased rates of PPD, PPA, and PTSD when compared to mothers of healthy term infants (Lotterman et al., 2019; Ionio et al., 2016; Helle et al., 2015; Lefkowitz, Baxt and Evans, 2010). Although outcomes are clearly documented, studies were done from the perspective of the mother and parenting in the NICU. Little is known about the holistic experience of these women beyond their identified symptoms and their maternal roles. Research of this population fails to address their nuanced and intersecting identities and leaves room to explore a more richly layered understanding of the experiences of women with infants in the NICU. This research study sought to understand women’s holistic experiences and influence the care they receive.

This qualitative study implemented Interpretive Phenomenological Analysis (IPA) to understand women’s experiences of self, life, and contexts of the NICU. IPA established a framework for descriptive experiences from participant perspectives. Here, women were invited to speak to the many identities held as she navigates the NICU and makes meaning of her experience. By highlighting the voices of women in a way that expands from their isolated role of mother in NICU research, this research uncovered and integrates more attention to these mothers’ holistic health and treatment.

Qualitative Research

Qualitative research is interpretive and seeks rich and thick descriptions to establish the meanings people bring to experiences in their natural settings (Creswell & Poth, 2018; Lincoln & Guba, 1985). Qualitative research is co-constructed between researcher and participant and is
The interpretations within qualitative research are derived from and based in the data collected. Data analysis can be either inductive or deductive to identify themes and patterns. Throughout data collection, analysis, and reporting of results, methods are implemented to help with trustworthiness of the study (Creswell & Poth, 2018). In qualitative research, the researcher holds beliefs and assumptions that naturally fold into interpretative frameworks which then guide the process of the research (Denzin & Lincoln, 2011). The beliefs and assumptions are based on the lens through which the researcher views the world (Creswell & Poth, 2018).

The following sections will address the interpretative framework I used for this study. After outlining the frameworks of my study, I will discuss the methodology and discuss the underpinnings of Interpretative Phenomenological Analysis (IPA). Finally, connections about how this interpretive framework and methodology was used in my study will be integrated.

**Interpretative Framework**

The interpretative framework is the set of beliefs and assumptions that guide the researcher throughout the study (Creswell & Poth, 2018). These assumptions of the nature of reality (ontology), the values I hold (axiology), how the researcher obtains knowledge (epistemology), and the procedures I use in my research (methodology) will all be guiding and underpinning my study (Creswell & Poth, 2018). This study was guided by the beliefs, ideas, and assumptions from frameworks of social constructivism and from a feminist approach.

**Social Constructivism**

Social constructivism is the belief that the individual’s reality is their truth. Rather than placing an emphasis on objective truth or one reality, social constructivism acknowledges the reality of each individual’s truth, and that multiple realities are constructed through lived
experiences (Creswell & Poth, 2018). Social constructivism focuses on the subjective meaning that individuals in specific social and cultural contexts experience. For this study, the lens of social constructivism was the guide for the examination of women’s experiences with infants in the NICU. The social and cultural interaction of the NICU are quite specific in nature. My study examined the subjective realities and meanings that women made while having an infant in the NICU.

The goal of this framework is to rely on the participants’ view as much as possible to inform patterns of specific situations and experiences. From the social constructivist lens, identifying patterns of meaning is an inductive process, moving from the specific and particular and expanding and transferring to the broad. For this study specifically, after the women shared their stories and how they made meaning of the significant event of having an infant in the NICU, themes from these participants are specific to the participant but also offer possible guidance to future women and the health care professionals who work in the NICU environment.

**Feminism**

Feminist theory emphasizes a transformative experience for women (Lather, 1991; Stewart, 1994). The roots of this study were formed by identifying the ways in which women are not being addressed, beyond their role as mothers, during their infants’ NICU stay. As conversation between my dissertation chair and I progressed, it became apparent that a feminist lens was naturally being integrated. Even the research question itself “How do women with infants in NICU care make meaning of their NICU experience?” is asked from a feminist lens, as it aims to address the woman herself and a transformative paradigm of the way women are viewed after childbirth. This study continually integrated a feminist lens as it privileges women’s
voices and expands understandings of women’s experiences in environments that traditionally privilege patriarchy and hierarchy (Lather, 1991; Stewart, 1994).

**Methodology: Interpretive Phenomenological Analysis (IPA)**

IPA is a qualitative approach, grounded in psychology, which explores lived experiences and allows the researcher to interpret participant perspectives. This method emphasizes how people understand their specific experience of a phenomena within their specific contexts (Smith et al., 2009). IPA first found its place as a psychological approach to understanding experiences in health and clinical counseling (Eatough & Smith, 2017). Researchers find appeal in this method due to its commitment to gain detailed understanding of an experience from the first-hand perspective of the participant, while giving value to subjective knowledge for psychological understanding (Smith et al., 2009). IPA conducts an in-depth exploration of what happens when lived experiences take on significance. For this study specifically, IPA was used to explore how women experienced and made meaning of having an infant in the NICU. This is often a critical incident that takes on significance and presents an opportunity to gain understanding of how mothers are holistically impacted. This research implemented IPA, due to its interpretative nature and the emphasis it places on understanding the significance and psychological essences of participants’ experiences. In this example, IPA’s underpinnings of phenomenology and hermeneutic methods allowed room to identify themes and patterns of women’s experiences and then to interpret their stories to identify the specificities and importance of the experience. IPA desires to first get as close to the participants’ view as possible in describing the perspective of the experience. IPA then aims to develop an interpretative analysis which allows the individuals’ perspective and description to situate within the larger cultural and social context (Smith et al., 2009). This study engaged with women whose infants had been discharged from
the NICU 6-18 months prior to their interviews in order to give time for adapting to having their infants at home and to allow women to have a reflective experience. For women who are journeying through the NICU with their infants, this study offers deeply detailed descriptions and interpretations of how meaning is being made with so much detail that later readers can apply the study to their own process.

**Phenomenology**

Phenomenology is the study of the human experience of a phenomenon (Creswell & Poth, 2018). Husserl posits phenomenology is the close and thoughtful examination of an experience and that the consciousness of the individual’s experience must be the focus of phenomenological inquiry (Smith et al., 2009). Other contributors to the development of phenomenological research methods include a move to the interpretative nature of the world and how the world is experienced in relation to others, to contexts, to language, and culture (Smith et al., 2009). Though IPA is phenomenological in nature it places emphasis on the interpretation of people’s experiences and explores how people assign meaning to their relationships and interactions to the environment. In this study of women with infants in the NICU, phenomenology acted as a guide as I examined and explored the phenomena of being a woman while having an infant in the NICU. The Interpretative nature of IPA allowed for discovery of how women story the significance of their infant hospitalized in the NICU.

**Hermeneutics**

Hermeneutics is the theory and practice of interpretation. This methodology is interested in the interpretation of texts, objects and concepts. The purpose is to make meaning via interpretation of language and experiences of specific life events that hold significance.
Hermeneutics requires sense making or interpretation, and assumes an active role of participants (Smith, 2007).

Heidegger focuses on threading hermeneutic and phenomenology approaches, emphasizing that interpretation is foundational to being (Smith et al., 2009). His position of the nature of reality is that nothing is ever revealed unless encountered and brought meaningfully into the context of human life, and that the human perspective is subjective and intersubjective in determining what is real (Eatough & Smith, 2017). Heidegger’s focus on perspective and the idea that human existence and experience is always in-relation-to exemplifies his beliefs of interpretation and meaning-making (Smith et al., 2009). Heidegger’s perspective offers the opportunity in my study to explore women’s experience of being in the world (while in the NICU) and the ways they interpret and made meaning of being. This in-relation-to focus also acknowledges the researcher and participant relationship interactions that influence the interpretations developed during data analysis. Heidegger acknowledges that the researcher brings in previous knowledge and bias as they analyze and interpret meaning of participants (Smith et al., 2009). In my study, I brought previous experience of having an infant in the NICU, which had influence on the interpretations. I remained aware and reflexive of this throughout the study.

IPA encompasses a double hermeneutic as the researcher is involved. The researcher is working to make sense of the participants’ story as the participant makes sense of an event through which they are living. “The researcher is trying to make sense of the participant trying to make sense of what is happening to them (Smith et al., 2009, p. 3).” Using IPA, I sought to understand how women, who are mothers to an infant in the NICU, are making sense of their personal world in this context. In using IPA I used both curiosity and empathy to gain a clear
understanding of each participant’s perspective. IPA is interested in the intimate details and lived experiences as told and viewed by the participant. With in-depth stories and intimate details, which gives texture and presence to the experience that women are living while having an infant in the NICU, there is also increased clarity for interpretation of meaning making (Eatough & Smith, 2017).

**Idiography**

IPA is idiographic in nature. Concerned with the particular in both detail and depth of analysis, but also in the sense of how particular experiences are being understood by specific people within that particular context. Unlike many psychological research approaches, IPA does not aim to generalize about entire populations, but rather focuses on a purposely selected group in order to provide information about the specific experiences with these specific participants (Smith et al., 2009). Using an idiographic approach is ideal with the population of my study as it provided opportunity for participants to share their detailed stories. A rich understanding of what it is like to be a woman with an infant in the NICU, and how these women make meaning of their own experiences can offer levels of detail that may be purposefully transferred to similar contexts and experiences. Results from this study are descriptive and allows potential readers to decide how they may apply themes and understandings.

**Role of the researcher**

“In everyday life each of us is something of a phenomenologist insofar as we genuinely listen to the stories that people tell us and insofar as we pay attention to and reflect on our own perceptions” (Halling, 2008, p. 145). This quote by Halling (2008) underlines the way IPA begins to use the researcher as a human being, with bias and subjectivity, and a co-construct of the research process. The goal of IPA is to gather an in-depth perspective and significance of a
specific experience through the lens of the participant. However, there is a clear understanding that the researcher cannot fully remove themselves from influence of the analysis. Particularly, the interpretive nature of IPA leaves the researcher involved in the co-construction of the data. There is value of being an “insider” regarding the particular contexts and events being explored (Smith et al., 2009). When using IPA methodology, those who have personal understanding of the context being explored may bring both meaningful additions to the research and must also remain acutely aware of their bias and influence on the data. Maxwell (2013) offers guidance about using researcher journals for reflexivity and to circularly explore the ways the researcher’s influence may impact interpretation of data. These tools will be explored in more depth when establishing trustworthiness in the research design. As the researcher, I worked to give voice and allow participants to use their own narrative to inform the perspective and meaning that their experiences in the NICU had for them personally. The interpretative aspect of this research was undoubtedly influenced by the lens I carry. As a NICU mother I have experience with the topic which was explored. Due to this, I had increased ability to build rapport with participants. I can speak the language of the NICU naturally and hold some form of understanding of the context and specificity of the NICU environment. Further, this same status required me to be acutely aware of my perspectives during the interviews so as not to misinterpret or lead participants. I also used reflexivity to identify the ways that my own worldview, experiences, and personal lens could influence the data analysis and construction of the results.

This IPA qualitative study explored the many aspects and intersections of women with infants in the NICU, and the meaning they are making of this significant event. Remaining in alignment with IPA methodologies, the research question guiding the study is:

How do women with infants in NICU care make meaning of their NICU experience?
Procedure for Participant Selection

**Sampling**

Purposeful sampling was used to gather insight from women who have had an infant in the NICU. Participants for this study were identified by outreach on social media platforms, including mother NICU groups. Initial contact with potential participants was initiated using social media messaging. The participants were selected first, because of the perspective they could potentially offer for the study of NICU women. That is the representation of the experiences, rather than representing a population.

Using IPA, and purposeful sampling the goal was to gain a detailed examination of a participant group that is homogenous in criteria. Inclusion criteria for this study invited women who are the birth-giving mothers of an infant in the NICU and whose infants have made a healthy recovery, and show no indicators of chronic, terminal, or developmental diagnoses. With this study, I sought a story that had a clear ending. Choosing to include mothers with infants who were well at discharge, offered clarity to the particular experience this study aimed to highlight; women’s experience while having an infant in the NICU, rather than the focus remaining on the infant’s wellness and their future. My study also included mothers whose infant was 6-18 months post-discharge. This timeline was selected with the desire to be both sensitive to mothers, ethical, and methodologically sound. This allowed for time to have passed and mothers to have adjusted to their new parenting role postpartum, while keeping it close enough to the experience of the NICU that women were still be able to access their experience in detail. The hope of this selected timeline was to gain detailed understanding of the significance of the NICU experience.
Within the selected homogenous group, I represented only small variations in the population (Smith et al., 2009). This variation will support capturing a variety of experiences within this selected group in order to give a richer and multi-perspective sense of the experiences of women with infants in the NICU. I recruited participants from the Northwestern region, which included participants from Montana and Oregon, in which the NICU uses FCC or NIDCAP approach to care. I recruited participants whose partner and parental status varied. Partner statuses included women who are both single and partnered. Partnered experiences are different than single parent experiences even from the basic standpoint of tasks of parenting and limited time and energy (Carter & McGoldrick, 1999) and thus it was important to gather data from both perspectives. I also interviewed women who already have children and for whom this infant was their first child. The experiences of first-time parents, with no other children at home, is different than that of having and parenting a second child (Bowen 1978; Krieg, 2007). First children require parent’s attention, often changing the focus of mothers from marriage to parenting. Second children require another reorganization of the system, drawing even further on energy and time demands (Krieg, 2007; Stewart, 1990). Adding a second child to the family structure allows for less of a focus on any single person in the system, changing the parenting dynamic, and all relationships in the system (Steward, 1990). The impacts and experiences to identity as a parent are also different, as parents to first and only children are working to learn and engage in a new role, while with subsequent children there is comfort and experience in the role (Bowen, 1978). These variations informed about each participant’s unique individual experience while having an infant in the NICU, while also considering differing experiences depending upon the woman’s current family composition and life worlds. I attempted to recruit participants who represent two incomes statuses. I desired to include participants whose family
income classified above the poverty level as well as participants whose income fell below in order to add to the variation and capture the range of the experience of women are navigating with greater or fewer resources. The federal poverty level (FPL) is annually issued by Health and Human Services (HHS). The FPL is determined by household income and family size. The current FPL for 2022 is $4,720 per family member. This means that for a family of three, the FPL is set at $23,030. This study will include women who fell both above and below the FPL according to income and family size (US Department of Health and Human Services, 2022). Unfortunately, I was unable to meet this particular criterion for maximum variation. Finally, I recruited white and non-white women to participate in this study. Racially and ethnically diverse women experience disparities in perinatal and postpartum mental health treatment (Iturralde et al., 2021; Kozhimannil et al., 2011). They face cultural, social, and individual barriers to treatment. Some of the barriers identified by Iturralde et al. (2021) include economic factors, language and cultural challenges, clinician related difficulties and a lack of social support. Other identified barriers to treatment involve challenges with getting out of work to attend treatment and trauma history. Including participants who are both white and non-white offers opportunity to explore and highlight differing experiences that women traverse while having an infant in the NICU, and for addressing these disparities.

<table>
<thead>
<tr>
<th>Parental Status</th>
<th>Partner Status</th>
<th>Income</th>
<th>Race</th>
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| • No other children at home  
• Other children at home | • Partnered  
• Single | • Above the poverty level  
• Below the poverty level. | • White  
• Non-white |
In the participant selection I aimed to have every variation represented in my study. I used social media for the first recruitment wave, asking interested people to respond and indicate their parental status, partner status, annual income and race. Based on these responses, I built a participant pool, and then invited some to proceed with an interview and informed consent. I then contacted others thanking them for their interest and informing them the interview slots had been filled, while also asking permission to contact them later if necessary.

**Ethical considerations**

I developed and sent a private message to interested participants explaining informed consent, and the expectations and criteria of being involved in the study. Participants were informed of expectations of multiple interviews and member check procedures to ensure that I captured and accurately portrayed their voice within the study. Possible risks and benefits of participating in the study were outlined in the informed consent. IRB approval was attained before reaching out to any potential participants. Shortly after beginning recruitment an IRB amendment was made changing the inclusion criteria from 6-12 months post-discharge to 6-18 months post discharge. An amendment was also placed in order to use the Zoom platform to conduct interviews, as the COVID pandemic created health risks for women with infants who were high risk. I used informed consent as an ongoing process, with each round of interviews, as well as during member checking. Part of the informed consent process included offering referral resources should someone be in emotional distress. Because IPA is analyzed and written with great detail, maintaining participant’s confidentiality was a priority and also a risk. Informed consent of the IRB discussed how precautions would be taken to aid in participants’ confidentiality. Specifically, confidentiality was secured by assigning participant aliases and altering identifying information when data was shared and disseminated.
Dispersion of power is another aspect which must be considered as I conducted this study. Power imbalances can be challenging in this type of research (Creswell & Poth, 2018). If participant experiences aren’t what I expect or don’t match my interpretation I looked closer and reevaluated the distribution of power. I sought consultation for these instances. I also held a keen awareness of the power dynamic, checking my power and working to operate with co-construction and shared power (Maxwell, 2013). As the researcher, I remained sensitive and responsive and consciously held the importance of working to understand the lived experiences of these women with infants in the NICU. I used reflexivity to explore my own biases, beliefs, and arising emotions as I conducted the research, and ultimately worked to bracket these. I also held awareness of my power in the role of researcher, offering open feedback and opportunity for member checks to revisit and reinterpret results that needed additions or did not sit well with participants.

**Methods for Data Collection**

I collected data from women with infants in the NICU using zoom semi-structured interviews. IPA stresses the need for the researcher to create guidance for the interview, while simultaneously allowing participants to share what is meaningful and valuable to their experiences (Smith et al., 2009). Prior to implementing interviews to participants, I engaged in a pilot test interview in order to practice and gain feedback about the interview questions. The pilot participant was a white, married, female, with no other children besides her NICU infant. She reported falling about the FPL, and was greater than 18 months post-discharge from the NICU. She offered feedback to be more direct with asking about the specific aspects of personal wellness. From this test, actual interview questions became more specific, asking about physical, financial, emotional, and mental wellness. It was this pilot test that also revealed a possibility
that women will desire to share their birth experience and the possible intensity of emotions the interviews could hold. I interviewed six mothers and in-depth interviews ranged from 60-90 minutes. Five questions guided the round-one interview. The structure of the interview was developed in such a way to fulfill both the need for reasonable time commitments and in order to develop deep and reflective interviews. I relied on follow-up questions in the immersive interview experience to support the progression of a deep and detailed understanding. IPA places a strong focus on allowing the participant to share what it is they find valuable and important to them and encourages the researcher to follow the participants on the path they take the interview. The questions in the interview schedule were open and allowed for expansion.

As participants had the opportunity to tell their stories and simultaneously make meaning of their experiences, I aimed to understand their lifeworlds (Smith et al., 2009). The semi-structured nature of the interview allowed me, as the researcher, to have a guide of what the interview may cover while also relaxing into the role of listener. The questions in my study were open and allowed the participants to talk at length and expand as they desired. The interview schedule was iterative and left room to be developed and changed as the interview progressed.

The interview protocol for the first round included:

- What can you tell me about your NICU story?
- Being a mother is often so central to women’s experiences in the NICU. Outside of this role, how did you experience the NICU? This could be the emotional aspects of yourself, the physical, spiritual, financial . . . anything that comes to mind. How were all parts of you impacted by this experience?
- What supports did you encounter during your NICU experience that were especially meaningful or helpful?
• What have you found especially challenging about your NICU experience?
• Is there anything else about your NICU encounter that you haven’t shared that is important for me to know?

Second round interviews were 30-60-minutes long, and continued building a full, saturated phenomenology of participants’ experiences. Second round questions were constructed to address any missing information and to further expand on first round analysis. Questions were open and offered opportunities for the participants to share in a conversational style. Interviews were conducted one-on-one, via the zoom platform, and were recorded. Interviews were transcribed by the researcher and identifying information was removed. Recordings and transcripts were securely stored on a password protected device.

**Methods for Data Analysis**

IPA analysis prescribes to a flexible, nonlinear set of principles and processes which are described as both iterative and inductive (Smith, 2007). The data analysis process moves from a focus on the specific experience of each participant and then into the shared perspective of participants. Data analysis then emphasizes both an understanding of the participants’ views of an experience, as well as the personal meaning-making the participants make of their experience. The interpretive nature of this method focuses on the ways the researcher makes sense of how the participant makes meaning of the event.

When beginning data analysis, after I transcribed the interviews, I initially read and reread the transcripts in order to become familiar with the data. By engaging with the data before beginning coding, this practice allowed for a slower, repetitive, and more intentional absorption of data and deliberate processing. It is during this reading that I began my own reflexivity, using journaling to write about my thoughts about the interview, and simultaneously
bracketing (Maxwell, 2013) to distinguish my own experiences and thoughts from the data. This also served as a self-care strategy in order to remain healthy during the research process. By reading through the transcripts as a whole, I aimed to achieve a fuller perspective of the progress of the interview and the development of the event being explored. This initial reading took a scoping view before I moved into analyzing and breaking the whole down into segments and pieces that IPA requires.

Next, I engaged in initial noting of each transcript. This involved a line-by-line approach when analyzing the data. I conducted initial noting from three separate perspectives. The three areas of analysis included examining the data and noting descriptive comments, linguistic comments, and conceptual comments. Descriptive comments focused on describing the content of the transcript and highlighting keywords, experiences, or events that described participants’ perspectives. I addressed linguistic comments make note of the specific use of language, including hesitations, laughter, phrases, metaphor repetition, and tone. Conceptual comments included the interpretative aspect of this methodology. This process examines the data at a conceptual level instead of a literal one, placing focus on the participants meaning making. Here the data expands as abstract concepts are explored (Smith et al., 2009).

After the initial noting, I coded for emerging themes from the data. At this stage of analysis, I shifted focus from working specifically with the transcript to working with initial noting. Here the hermeneutic circle began to surface as the experience moved from viewing the interview from the whole piece, to fragmented parts as I began to make connections and organize the data. As I began to structure and analyze initial notes, the interpretive nature of the research also began. During this stage of analysis themes started to emerge in brief phrases, which reflected both the words of the participant and the interpretation by myself, the analyst. The goal
of discovering emergent themes is to capture the psychological essence of the particular part of the transcript while striking a balance between abstraction and the particular. At this stage of analysis, the themes reflected the words of the participants as well as the interpretations I made of the data. I used NVivo software as an organizational tool, inputting initial data and using the software to organize data into emerging and subordinate themes.

Once initial emergent themes were analyzed, I took a scoping look at all of the current themes of the transcript. From here I used abstraction, pulling together similar themes and discovering connections and patterns. Other skills I used to help arrive at superordinate themes include numeration, contextualization, narration, and polarization (Smith et al., 2009). I identified possible super-ordinate themes, which are the higher-level themes that house other themes beneath it.

Every aspect of this sequence occurred for each participant transcript. After themes had emerged and I made connections throughout the transcripts, I followed the next step in IPA, to move on to the next case. I then repeated the process of reading, noting, coding, and developing emergent themes. During this step new themes emerged. Although easy to stay in-line with already identified themes I remained open to the data which allowed for novel themes to continue emerging.

After all individual transcripts had been coded, and emergent themes recognized, the final step was to discover and explore the patterns and alignments across all of the cases. This was done by laying out all of the super-ordinate themes in each case and developing connections and patterns among these themes. I began to identify these themes by moving from specific instances into higher order concepts and theoretical thinking which supported identification of themes across cases.
Once all final themes were identified and labeled, I then created a chart to display the superordinate themes and the emergent themes. Here I extracted phrases from participants to help name titles of themes which illuminated the dialogues with participants which grounded the interpretation of each theme in relevant data.

After coding and developing emergent themes across cases, I examined the data and analyzed for areas to be expanded upon and considered what may be altogether absent in the data. These areas guided the development of second round interview questions. Upon second round data collection, I reengaged the analysis process in order to confirm, relabel and develop the final set of themes from the data, arriving at a phenomenology of women’s experiences in the NICU.

**Establishing Trustworthiness**

Lincoln and Guba (1985) outline trustworthiness as the credibility and quality of a qualitative study. Particularly, trustworthiness is evaluated on credibility (results are believable from participant perspective), dependability (degree to which the research process is documented and can be followed), confirmability (degree to which the results could be corroborated by others) and transferability (degree to which results can be transferred to other contexts by the person wishing to do so). There are many ways that trustworthiness is implemented throughout qualitative research. Researchers use inquiry audits, member checking, saturation of data and prolonged exposure to increase trustworthiness (Creswell & Poth, 2018). Lincoln and Guba (1985) also state that the use of rich and thick descriptions is yet another way to develop credibility. This study of women with infants in the NICU will develop thick and detailed descriptions of women’s experiences, and the meaning they made, while having an infant in the NICU. I used member checking, reflexivity, prolonged engagement, inquiry auditing, and
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Yardley’s criteria (sensitivity to context, transparency, commitment and rigor) (Yardley, 2000) to develop trustworthiness of my study.

**Member Checks**

I used member-checking by bringing the results from the data analysis back to the women whom I interviewed to check that I correctly portrayed the perspectives and experiences they offered (Creswell & Poth, 2018). Participants had individual opportunities with me as the researcher to suggest areas that need to be revisited, reinterpreted, removed, or added. Strong rapport with the women was important to develop as this is where a power imbalance can become an ethical challenge. With a trustworthy alliance between myself and participants, there was decreased potential for power imbalances and thus increased possibility for honest responses from participants during the member check. This co-construction and checking of interpretation increased the accuracy of the participants’ experiences, making sure that it was the essence of their experiences and meaning being presented.

**Reflexivity**

Researcher reflexivity is another approach I used to establish trustworthiness in my study. Maxwell (2013) outlines the responsibility that a researcher has to engage in this process not only in the beginning of a study but throughout. Reflexivity is thoughtful attendance to the ways in which I may be informing the data (Maxwell, 2005). As mentioned previously, I engaged in personal reflection and reflexivity of my own pulls, biases, and perspectives via reflexive journaling throughout the project. Reflections also included my internal thoughts and ways I may have influenced both the collection and interpretation of the data.

**Prolonged Engagement**
I used prolonged engagement to accurately portray the individual participant voices among the whole. I built strong relationships with participants using empathy, reflective listening, openness, and acceptance throughout the interviews. Prolonged engagement was achieved through the building of strong relationships as I spent multiple hours with participants as well as engaged in member checks. Due to frequent and quality connection with the participants in interviews the development of trust was established between participant and researcher. This trust supported increased depth to detailed experiences in the data. Due to my personal experience navigating the NICU I was aware of and attuned to the culture of the NICU. This allows for relationship building and prolonged exposure. This same argument also required me to be reflexive and conscious of the ways that my experiences varied from the participants I interviewed.

**Inquiry Audit**

Inquiry audits rely on a researcher outside of the data collection and analysis to support and offer feedback (Lincoln & Guba, 1985). The inquiry audit aims to ensure the study was done with rigor and consistency between the data and interpretations. I met regularly with Dr. Kirsten Murray who served as my inquiry auditor. During these meetings a review of data, including of interview transcripts, audio recordings, initial notes, emerging themes and subordinate themes were discussed and explored to assure that I was representing the data and participants’ stories with accuracy.

**Yardley’s Criteria for Validity**

**Sensitivity to Context.** As a mother who experienced having my infant in the NICU, I have an awareness of how the NICU can be. This awareness allowed me to enter into this study with sensitivity towards women’s stories, being open to hearing and holding their stories, while
also remaining open to variation from my own experiences. I used this principle throughout the entirety of the study. This sensitivity to context is reflected by recruiting participants at 6 months-18 months post-discharge. I held respect for the possible experiences that women have experienced and be sensitive by allowing months of time post discharge, that they may be settling into the routines of parenting and begin integrating their experience. During recruitment I was respectful and remained cognizant of the needs of participants. As participants were chosen I was deliberate in building rapport. I aimed to exude empathy throughout my interviews and engagement with participants and with the data. I also gave attention and detail to the analysis of the data and showed this sensitivity to context by thoughtfully considering and extracting data that supported the emerging themes. This gave rise to the voice of NICU women. Attention to the sensitivity of context added trustworthiness to my study by using the data to accurately portray the participants’ stories and meaning they made of being a woman while having an infant in the NICU.

**Commitment and Rigor.** I gathered extensive details from my interviews with participants and, as mentioned, was intentional in my selection of participants to ensure that the data speaks to the group I identified. I engaged in recording, and transcribing data and remained immersed in the content to develop a deep understanding of what the data was saying. I used multiple interviews to reach saturation of the data. I conducted my analysis in a theoretically grounded way with invested time, thoughtfulness, and attention to detail.

**Transparency and Coherence.** I used transparency in all parts of my study. I shared how participants were selected, and the process and my impressions of our interviews. I used transparency by inviting my inquiry auditor into my own reflexive journaling and exploration and access to raw data. I was transparent with my inquiry auditor when I encountered challenges
or differences in my exchanges with participants, inviting feedback and perspective. I was open and clear with participants about the aim of the study, and methodological decisions. I worked to make the results coherent and answered the research question with clarity. I maintained the underpinnings of this method of research, showing the roots of phenomenology and hermeneutics in my writings and interpretations.

**Impact and Importance.** My study produced research that tells of something valuable, important, and useful for women who have an infant in the NICU, and their providers and counselors. The results speak to participant experiences and highlight possible ways to care for the women who encounter this significant event. Impact and importance give an indication of the validity of the study and how well the research was conducted.

**Positionality Statement**

I come into this study as a white, cisgender, 35-year-old woman and mother. My own experiences of having an infant in the NICU as well as experiencing the vast number of women who approached me during our own NICU stay, have informed the foundations of this study. As a professional counselor, I have a deep interest in the ways that caregivers are impacted by the caretaking role and have developed and dedicated a large part of my practice to offering support to caregivers. My professional and personal experiences have come together to influence me to research the holistic experiences of women who are navigating having an infant in the NICU. I desired to gain a deeper understanding of participants’ holistic experience and how they ascribe meaning to it, ultimately developing a resource of support for others who navigate this significant journey.

**Summary**
Though there is a vast array of literature understanding what mothers experience with regards to parenting in the NICU, the exploration of women’s holistic experiences beyond her role as caregiver has yet to be explored. Gaining an understanding of the many ways the woman is impacted while having an infant in the NICU has little, if any, empirical support from the literature. I conducted an IPA study to shed light on the layered experiences that the NICU mother has, centered around the research question: How do women with infants in NICU care make meaning of their NICU experience?
Chapter III: First Round Analysis

This chapter introduces participants and discusses themes from first-round analysis. Six superordinate themes were coded from first-round interview transcripts: Welcome to the NICU, Medical System Encounters, The Juggling Act, Deep Dark Battle, Escaping the Spiral, and Post-Discharge Experience.

Participant Descriptions

I conducted six semi-structured interviews after receiving approval from the University of Montana Institutional Review Board (IRB). An amendment to the IRB was included and approved to increase the post-discharge timeline of mothers from 6-12 months to 6-18 months.

The six participants are women with an infant who was hospitalized in the NICU. All participants will be referred to by pseudonym: Abby, Ellie, Andrea, Brooke, Lindsay, and Jessie. Abby identifies as a white woman. She is a single mom, with two children at home in addition to having NICU twins. Ellie identifies as a white woman. Her NICU infant is her first child and she is in a heterosexual marriage. She works as a nurse in Mothers and Babies wing as well as in the NICU. Andrea is a white woman who is in a heterosexual marriage and has no other children at home. Lindsay is a white woman in a heterosexual marriage with a first child in addition to her NICU son. Jessie is a single, Native American woman who has no other children at home. All of the women in this study reported income above the poverty line.
Purposeful sampling was used in this study. I began recruitment via outreach on social media platforms and outreach through NICU and professional colleagues. Through this later point of contact, Abby volunteered to participate in the study. Ellie, is a nurse in the NICU, learned about the study from her colleague, and established participation contact through a social media platform. Andrea and Brooke made contact through NICU Mom groups. Lindsay became aware of the study by word of mouth from NICU Moms and a point of contact from my doctoral student research group. Jessie also learned about the study through a contact in my doctoral research group. Once participants communicated interest in the study, they completed a demographic questionnaire establishing data about their partner status, number of children, annual household income, and race. The demographic data was then examined for maximum variation criteria to establish a range of experiences within the homogenous group of participants.
(Maxwell, 2013). This study included participants who were both white and non-white. I also recruited participants who were partnered and one participant who was single. Finally, participants who had other children at home, as well as who had no children at home were recruited for this study. These aspects of maximum variation were met. Unfortunately, despite recruitment efforts, the criteria to represent two income statuses went unmet. All of the participants in this study reported falling above the poverty income threshold. Participants were included in the study if they were the birth-giving mother, their infants were 6-18 months post-discharge from the NICU, and if their infants were now healthy and did not have chronic long-term or terminal diagnoses.

Each woman participated in an initial interview lasting between 60-90 minutes. They discussed their experiences of being a woman while having an infant in the NICU. I developed an interview protocol of five open-ended questions that guided the interview:

1. Can you tell me your NICU story?
2. In the NICU so many parts of yourself can be affected by the experience, these can be spiritual, financial, emotional, physical...when you think about these pieces of yourself in the NICU what comes to mind?
3. What supports did you encounter during your NICU experience that were especially meaningful or helpful?
4. For you personally, what have you found especially challenging about your NICU experience?
   • What did you need or would have been helpful to you?
5. Is there anything else about your NICU encounter that you haven’t shared that is important for me to know?
I used a semi-structured interview approach, asking additional clarifying questions when necessary. Interviews were completed on zoom, after an amendment to the IRB was approved to gain permission for this interview platform. The change of interview platform was altered from in-person to zoom, due to women’s at-risk infants and COVID-19 exposure. After conducting the interviews, I completed transcription and began the coding process.

**Data Analysis**

I conducted three rounds of coding with each participant transcript. I first began by reading and rereading to gain a scoping perspective of the whole interview. Then, I engaged in the initial noting of each transcript. This involved a line-by-line approach using three separate perspectives. The three areas of analysis included focused notation of descriptive comments, linguistic comments, and conceptual comments (Smith et al., 2009). Descriptive comments consider the actual content or the “what” women shared about their experience. I noted and coded keywords, experiences, or events that revealed participants’ perspectives. Next, I noted all linguistic comments. This coding considers how women share their experience. In this layer of coding, I explored participants’ use of specific language, sounds, silence, metaphors, repetitions and tone. Last, I reread the data and made conceptual comments. I examined data at a conceptual level instead of a literal one, placing focus on the women’s meaning making. I developed codes and emergent themes for each transcript and then examined the patterns and themes which aligned across all of the cases. I organized codes and emergent themes using NVivo software to manage the data.

**First Round Results**

The experiences of women with a NICU infant were captured in six superordinate themes: **Entering the NICU, The Forgotten Mother, The Juggling Act, The Deep Dark**
WOMEN’S JOURNEY THROUGH THE NICU

Battle, Escaping the Spiral and Post-Discharge Experience. Each of these themes is characterized and texturized using a structure of subcategories, properties, and dimensions explored in detail with each superordinate theme. Throughout the narrative I will use text formatting styles to distinguish Superordinate Themes, Subcategories, Properties, and dimensions. See Figure 1 for the conceptual map that indicates the superordinate themes, subcategories, properties and dimensions of women’s experiences while having an infant in NICU care.

Figure 1

Conceptual Map of Women’s Experiences in the NICU following first round analysis

Entering the NICU
- Sudden and Unexpected
  - Disruption of Pregnancy
  - Entering Birth Alone
- Loss of a Dream
- New NICU Motherhood

The Forgotten Mother
- Overriding the Mother Role
- Detached and Dismissive Staff Responses
  - Role Rigidity
    - Emotional Handoff
- Infrastructure Collapse
  - Physical
  - Staff Challenges
- Frustration with System Communication
  - NICU Prep while Pregnant
  - Communication of Treatment Plans and Changes

The Juggling Act
- Logistical Tasks
  - Self-Sacrifice
    - Ignoring Physical Needs to Care for Infant
  - Work & Finances
  - Schedules
- Mental and Emotional Tasks
Maintaining Proximity to Infant
  ▪ Fear of Being Unknown/Detached
  ▪ Pain of Being Away from Infant

Alone
  ▪ On My Own
  ▪ Physical Space
  ▪ COVID as a Complication

Nonlinear Medical Progress
  ▪ Pregnancy
  ▪ NICU
  ▪ Trauma with Infant’s Struggle

The Deep Dark Battle
  • Lonely
    ▪ Isolated
    ▪ Emotionally Alone
  • The Pervasiveness of Death
  • Good Mom/Bad Mom Dichotomy
    ▪ Good Moms pump and Produce Milk
    ▪ Good Moms Spend all of their Time Present
    ▪ Good Moms are Selfless
    ▪ Good Moms Don’t Ask for Help
    ▪ Other Moms
  • Guilt
  • Failure
    ▪ I’m the Failed Vessel
    ▪ Helplessness
  • Shame
  • Despair and Hopelessness
    ▪ Desperate to Get Home
    ▪ Personal Despair

Escaping the Spiral
  • Avoidance and Distraction
  • Family
  • Social and Online
  • Attuned Care
    ▪ Staff Support for Relational Health Between Mother and Baby
    ▪ Trust in the Medical Support
  • Counseling
  • Mom Pride
  • Spirituality
    ▪ Making Meaning
    ▪ Spirituality
Entering the NICU

Entering the NICU is characterized by an often abrupt and surprising entrance. Receiving NICU care is often not part of the plan women had during their pregnancy, or for their deliveries, or the beginning of their infant’s life. Subcategories of this theme emphasize the sudden and unexpected experiences women navigate due to the premature delivery, or a turn of events during their pregnancy that require NICU care. Participants articulated this sudden admittance as leaving a wake of ambiguous grief of the plans and dreams the women had for the birth and greeting of their infants. This theme highlights the unknown aspects participants must navigate rapidly as they enter the NICU experience with their infants. The subcategory of New NICU Motherhood, which also has layering of new to motherhood built into it, helps contextualize the experience of having to learn quickly about becoming a NICU mother. It magnifies women’s experiences of having to rapidly consume information about the NICU itself, their babies’ medical condition, and the medical system once these women’s infants were admitted to the NICU.

Sudden and Unexpected

All of the participants described their birth and entry into the NICU as sudden and unexpected. In many of the cases, participant pregnancies were following a normal trajectory until a disruption led to medical intervention, monitoring, or the sudden birth of their infant. All the
women in the study began their NICU stories with pregnancy, and then their birthing experiences; all by emergency C-section due to medical concerns for either themselves or their infant. Abby clearly stated the challenge she faced due to the surprise of a premature delivery of her daughters, “So it was just so hard because it wasn't at all what I wanted or expected.” The women underlined the prematurity of their pregnancies ending and the necessary adjustment to a new plan. Participants experienced their logistics being disrupted due to the suddenness of the impending hospitalization and birth. Jessie discussed being unprepared for her sudden hospitalization which resulted in an unplanned relocation to a hospital away from her hometown.

    So, I think the one thing . . . being away. . . . We weren't comfortable just being physically like away from home. Kind of out of our element… that was another thing. We didn't have clothes . . . so I had to borrow like my mom's clothes, and had to buy, like you know, like other stuff.

Ellie discussed not being physically and logistically ready for the early arrival of her infant. She reported, “We didn't have, because everything happened so fast, and because he was eight weeks early it wasn't like we had the car seat in the car…You know we didn't have a hospital bag packed, like it was just kind of… I went to the hospital. I had a baby.”

**Disruption of Pregnancy**

    All of the women experienced a sudden difficult change in the nature of their pregnancies. Many highlighted a disruption due to medical threat of their own health or concern for the infant. Abby identified having an expectation that her pregnancy would be carried to term in her home. She reported being surprised when this plan did not come to fruition and she was instead presented with unexpected information:

    I was thirty-two weeks, and I just started having contractions and stuff at home, and then went just to get checked out the next day, and was expecting them to just say, ‘Oh, no, you just need to take it easy and go home,’ and that wasn't the case. The case was that my water had broken. It was leaking which I felt, but I didn't know that they were going to say, ‘Well, now you have to stay here until you deliver.’
Ellie shared about the quick shift in her pregnancy journey due to her own high-risk health concerns. She reflected on the sudden possible implications she had to face:

It all ended up going down very quickly: When I went to the hospital my blood pressure was very high, and so they said, 'we’re going to keep you. Give you steroids. Try and get you through, you know, to like thirty-four weeks would be like our goal, thirty-seven if we can make it.' At that point, I was thirty-two weeks and one day.

Jessie also noted her experience attending a routine prenatal appointment. To her surprise she was immediately hospitalized due to medical threats to both herself and her infant. She shared about the immediacy of the concern which resulted in rapid changes:

I was (slowly) just going in for a prenatal appointment. Um, that got delayed a week due to weather. So, I'd traveled from (bigger town) to (hometown) for prenatal care….and it was great that I was able to see [Doctor] when I got there, because she um… like my blood pressure, was pretty elevated. She noticed it, and then it got like higher and higher. It was like 140. Um, I think, over like 100 or something, but then it got, it had increased, or like up to like 170 over something at some point, so it was like on like the verge of like me seize…, like having seizures. So, she was like, ‘you need to like be sent out like immediately.’

Lindsay also discussed the unexpected change in her health identified during a routine check-up. This sudden complication not only required immediate hospitalization to stabilize her, but also resulted in a necessity of an early and pressing delivery of her infant the same day: “And so I had just gone in that day for one of my, you know, for the one of my appointments…and basically because my blood pressure was so high and my kidneys and my liver and everything. So, then they said, um, you know, ‘that he had to be born today.’

**Entering Birth Alone**

All of the women in this study experienced a sudden birth via emergency or urgent cesarean section (C-section). Participants explained the suddenness of the decision by doctors to deliver their infants. Participants expressed experiencing the decision and action of the event as
happening fast, and without much time for mental preparation. Brooke speaks to the promptness of which her doctor made the decision to deliver her infant immediately:

So they called in the Resident who was working with [Doctor], and um, you know they call [Dr. X], and they came right over, and we had to deliver...So we had to have an emergency C-section right there, like right then and there, it happened so fast.

Participants also described the grief and fear they experienced as they were separated from their family as they unexpectedly entered into urgent deliveries and admittance into the NICU. Women described being afraid and sad as they navigated their experience. Due to the urgency of the delivery, Brooke began being prepped for surgery without the support of her husband. She shared:

It's like it happens so fast, and you know [Dr. X] is on the phone with my husband, and we live in (town), and he's like ‘you need to get here like now, because we're wheeling her into the operating room right now.’ …And um, and then I, my husband, finally gets in just as they’re um getting me prepped for surgery. It was like, right in time.

Similarly, Abby identified the way she had to change her personal plan of support during delivery: “and then my two support people were not there, and so they had to like hurry and rush and try to get there on time, and then they only let one person come in with me. So that was upsetting for me.” Lindsay also discussed her experience of navigating the unexpected news of finding out she would be delivering early, without warning. She discussed feeling emotional distress from the surprise.

And I don't know, I was feeling like really um emotional, too, because um, because I hadn't known that morning that I was like gonna have him...It was like really sudden taken into the hospital, and, like you're going to have a baby today, and you won't be going home for six days.

For Lindsay this sudden and unexpected event meant that she would be unable to see her older son before the birth of their new baby. It also meant that for six days she would be unable to visit
or see her son who was at home and he was unable to enter the NICU or Hospital because of heightened visitor restrictions due to the COVID pandemic. For Lindsay the outcome of this separation from her oldest child, due to the sudden and unexpected birth of her infant son, had major impacts on her emotional wellbeing:

I was feeling like really um emotional, too, because um, because I hadn't known that morning that I was like gonna have him and um, and I had like wanted to see my older son one more time um, and like know that I was, and say like bye to him. So that was hard, especially because then I was in the hospital for um six, six or seven days, and so I didn't, and I couldn't see him because he couldn't come in because of COVID. So that was really hard.

**Loss of a Dream**

Several of the participants discussed their experience of grief surrounding the loss of their dreams and plans for the birth of their infants. They shared about the desire to hold their infants upon arrival. They noted the long-held dreams about their infant’s birth, and their actual experience of being met with NICU staff whisking their infant away. Participants shared their emotional experience of these losses, including Ellie: “I didn't even really see him, which is (pause, crying), you know, like a moment that you, I think you kind of dream about, for you know, as long as you have.” This highlights the suffering embedded in the loss of the dream she had about this special moment. Abby articulated the emotional aspect of having her infants being taken to the NICU for immediate medical intervention and her sorrow surrounding not being able to hold her daughters:

The first one was the one with the arrhythmia. Her name's [Sophia]. Um, they hold her up, just like briefly, as they were like walking by like here she is, and then took her away, (tearing up) …and so I got to see her (the second baby), for like a little bit longer, and then they took her away also. Um, I was hysterical. I was crying a lot. Um, it's like they're not in the same room with me.

Lindsay clearly identifies the grief experience of not being able to hold or welcome her infant as she had planned, “I just felt like that was just really hard. Um, and you know just that feeling of
like that's not the way that it's supposed to be… That it was totally a feeling of, there was
definitely a feeling of grief.” Jessie also identified having a dream about her first interactions and
connections with her infant, and then experiencing the opposite. She reported, “His dad, I told
his dad to go with him to the NICU, and then I got left there (laughter), and then brought to the
[post-op] room. So, we were separated. I didn't even get to like, touch him, or really see him until
the next day.” She continues, describing the vacillation she experienced between the hope of the
dream and the stark opposition of her reality:

In the moment it was really hard, I think, just thinking about not having that immediate
interaction, because you have this like dream (emphasized) of like, ‘Oh, when I meet my baby it's gonna be this beautiful moment,’ and it was like the opposite. I mean. It was a
beautiful moment, but at the same time, like I would just remember laying on that, you
know, like the, the bed. Um, and just like shaking because I was so nervous and cold in
that operating room. And you're just freaking out because you're like, ‘I'm going to be a
mom.’ But then, yeah…

Several of the participants discussed acute awareness of their grief, not being able to greet and
keep and hold their babies. An example of this is highlighted when Abby articulated her
awareness, and simultaneous frustration, about the loss of the “normal experience” regarding
having a baby. “Um (pause) And [the Social Worker] was really nice, and said, you know, this
is completely normal, and it's okay to feel this way. And I’m like, it's not okay for me, though,
you know…. It was hard because it's like, I don't want people telling me this is normal. It's not
normal.”

Abby described the delivery of her infants and the immediate separation between them.
She said,

The first one was the one with the arrhythmia. Her name's [Sophia]. They hold her up,
just like briefly, as they were walking by like ‘Here she is,’ and then took her away,
tear...
She also shared about her experience of being unable to hold her daughters once they were in the NICU. She stated, “So then I could go and see them. The first time I saw them I was not able to hold them. I could put my hand inside the little incubator and touch them, and that was it…."

Jessie also identified the challenge of not being able to hold her son, “Yeah, So I was… it was a horrible first experience meeting my baby, and I didn't even get to hold him right away.”

**New NICU Motherhood**

*New NICU Motherhood* is about the lived experience of becoming a NICU mom and not yet knowing how to engage in the role as a NICU mother. This experience was discussed by first-time moms as well as mom’s that had other children at home. It’s a layered experience of new roles in which it became evident women experienced a sense of adjusting to mothering their NICU infant, while also in the foreign environment of the rarely talked about NICU. For most of the women in this study, the NICU was an unknown environment and experience, only known by entering into the experience. For Ellie, who works as a Nurse in the NICU, the environment was more familiar. Despite having understanding, even she discussed how the experience was unpredictable, uncertain and distressing. Women who already had children, and the participants for whom this child was their first, both described the peculiarities and uncertainty about this task they faced.

Jessie conveyed her openness to receiving support from the medical staff about mothering. She highlighted the newness and uncertainty of both becoming a mom and becoming a mom with the added uncertainty of having an infant in the NICU. She stated: “We are first time parents, we're in the NICU, . . . . and so, you know we'll take the help for sure.” Abby, despite having two other children at home, expressed more distress and uncertainty about the newness of becoming a NICU mom. She shared: “So I had the C-section, and I've never had a
child in the NICU, ever, so I didn't know what to expect, and I was like asking them like, “Okay, Am I going to get to hold them or see them, you know…”

Ellie, a NICU nurse, was able to articulate the challenge of becoming a first-time mom while having her infant in the NICU. Although she is a NICU nurse she shared about having to learn this role without the support of her own mother. She shared about how restrictions and precautions due to the COVID pandemic prevented her mom from being able to enter the NICU. Ellie shared,

So, it was like I couldn't even have my mom come in. It just was my husband and I, and it's like you're learning how to be a mom while also, like you're just surrounded by like strangers, you know, and like the nurses are great and the doctors and, and it's not the replacement for like that village of like moms and aunts and grandmas and you know, it's like, like that's really important. Um. And yeah, to not have that just was hard, just to even figure out how to like burp him, and trying to breastfeed and just doing all of that alone was so isolating.

The Forgotten Mother

The Forgotten Mother category embodies the ways women experienced a bypass of her own personal care and of her role as a mother. This category recognizes that although the NICU is a place of respite for their infant, the system that participants were navigating also held negative experiences. Participants discussed the ways that medical staff overlooked their prominent need to offer care to their infants, and also were unable to address her personal care and needs, leaving participants feeling disconnected and ignored. All participants discussed their frustrations and disappointments with the disconnected care they received by the system. They described feelings of being overlooked for multiple reasons: system infrastructure, personal engagement, and in some instances, by the medical staff. The Forgotten Mother highlights the ways that the women had negative experiences regarding the bypass of her personal care, role as
the mom, and emotional and mental wellbeing. Participants also recognized the supports they received from the medical system, and the aspects of the experience that they deeply valued.

The subcategory, *Overriding the Mother Role*, highlights how women felt displaced and bypassed in their role as the mother. Women identified *Detached and Dismissive Staff Responses* as direct ways of disregarding the women in the NICU. They also discussed the ways in which staff, at times, were unable to engage emotionally, or outside of their role as part of the infant’s care team. Women described a subcategory of *Infrastructure Collapse* of the medical system in which the environment, physical design, staffing challenges and even COVID policies created difficulties which negatively impacted them (WHO, 2020). Another subcategory that emerged from participant interviews was *Frustration with System Communication*. This emerged as participants shared their deep frustration with absence of information from staff and with changes to treatment for their infants.

Several participants shared their experience of their personal care being unimportant, or not qualifying for staff care. Women identified their personal care needs as mental, emotional, and physical. They explained, in multiple ways, their sense that the staff was specifically there to help the babies survive, and not attend to the mothers’ emotional or personal needs.

The advancement in medicine in the past several decades has led to an increase in collaborative approaches to care. One such development is in the form of Family Centered Care (FCC). FCC acknowledges the patient within their family system, while the infant remains the identified patient. Even with standards of FCC the women in this study address their experiences of their personal needs not taking precedence or acknowledgement.

Andrea identified the nurse’s role to support and to attend to the infant’s medical care rather than to her needs. She stated,
they can talk to you a little bit and just make sure they're asking you know, how are you feeling (physically)? Are you okay? What’s... you know, and kind of chat with you a little bit. But I mean, you really don't get that one on one...because they're so busy. And then you know, an alarm goes off and then they're running out of the room or they have other babies that they need to check on

Later, Andrea continued, “I mean I just think the nurses are just so busy. And not that they are not, you know, sympathetic or empathetic to your situations, because I know that they all are, and they all care about the babies (emphasized).” Abby gave a summary of her overall experience in the NICU pointing out that her infants received supportive and solid care as patients. She also magnified her personally negative experience, which points to the possibility for future support to the mothers of the NICU:

    Yeah, it's, I mean, everything worked out great, and you know, overall, even though my experience was extremely traumatizing and (pause) and awful and sad and depressing like, I wouldn't change it. I mean, like, yeah, I wish I wouldn't have had to be in the NICU. But…you know they [infants] got the care that they needed. They got the attention that they needed. They got the, you know, the treatments that they needed, and we survived it.

Brooke gave a direct statement about her experience of feeling like there isn’t someone specifically there designated to attend to the woman’s needs. She stated: “I feel like Moms are kind of forgotten in the NICU in general. Right? It's like Oh, you had your baby early, you’re in the right place for them to survive.”

    Andrea reiterated this sense by naming the lack of available support for the mother. She shared her experience that the Hospital’s social worker was unavailable to truly support her. She shared,

        And I just feel like yeah, there isn't really, I mean, there's the social workers, but they're not really there for you... And I don't even think, I don't even think I met our social worker. She, I think just read our paperwork and like called me one time to make sure that we had oxygen lined up at home and we had a ‘fit’ (up to code) house, too. Yeah, and that was it.
This statement magnifies what is not being offered: the lack of availability of emotional support for the women who are faced with enduring the NICU experience. Ellie also discussed how the woman herself is bypassed. She identified that often the title of ‘Mom’ is the primary title for the woman. She spoke about how after her experience in the NICU, she began learning and using the names of the woman that she was interacting with in the NICU. She identified that by only calling her “Mom” rather than her name, women become dehumanized. She stated:

I try now, as a nurse, to like always get to know my patient’s names. That I’m not just calling them “Mom,” because that's kind of like something we don't even think about, you know, and then referencing them...Yeah, just calling her mom. It's like, well, no, she's a person. And you know she's just been through this big thing...so that is something.

Andrea describes an experience of being only a few days post C-section and needing to get to her son. Due to a lack of available wheelchairs, or her nurse, Andrea made the decision to take an unsupported walk from the Labor and Delivery wing of the hospital to the NICU. She reported how the two wings were located at opposite sides of the hospital, creating quite a challenge for her to overcome. She shared:

I still remember this day like it was yesterday (laughing). It was, I think it was my last day when I was still, before I had gotten discharged um, and there were no wheelchairs available, and I was like “I am gonna walk, I need to go see my baby” and I am walking like holding on to the rail (laughter), and I walked the whole... my nurse hadn't come in yet to give me any pain medication, so my pain medication, it was just, like, was completely wearing off...I was like in between that point and my nurse obviously went into my room and was like ‘oh she is not here, she is probably visiting her baby.’”

Here, Andrea highlights her deep desires to parent her infant, and a bypass of her needs physically and maternally. Andrea continued on with her memory,

Then my nurse was like ‘there you are I’ve been looking for you’ (laughter) and she is like ‘you are so overdue on your medication’ and I was like ‘I just had to go see [Sam], and no one was there, and I assumed you were taking care of someone else, and so I just wanted to go and see [Sam].’

**Overriding the Mother Role**
Overriding the mother role represents the ways women experienced their maternal responsibilities being infringed on by medical personnel and even at times by medical protocols. Participants identified a deep desire and longing to care for their infants, and simultaneously described various experiences of how this opportunity was taken from them. Abby framed this as the needs of the nurses, at times, overtaking her own need to mother: “And then, like the other nurses, they were more like ‘Oh, here I’ll give them a bath. Let me just do it,’ and you know, to try to hurry and do it and get it done and over with.”

Women described a multitude of ways they experienced staff Overriding the Mother Role. In some cases, participants described how the loss of the opportunity to engage in the maternal role, was disguised as being in the best interest of the woman herself. Instead of “taking away” the messages from staff were that of “giving back” of time and rest to the woman while they cared for her infant. Participants Ellie and Abby shared about their experience of being encouraged to rest and heal, at the expense of their opportunity to hold, feed, and care for their infants. Although the intentions of staff seem supportive, participants identified this as a negative experience rather than a positive opportunity of receiving. For example, Ellie shared about her experiences of nurses encouraging her to go get some rest, while they cared for her infant. She expressed, “But like as a mom, it's like: How in the world is she supposed to go back to her room, where she expected to have her baby, and sleep, you know? Like this isn't, this doesn't, like while she [mom] just has nannies take care of her baby.” She went on to explain an experience of watching nurses offer this statement to another NICU mother, hearing sentiments of, “She's [the baby] good. She's in good hands. Go get some rest, take advantage of us.” Ellie understood the nurses’, who were also her coworkers, positive intention, and also experienced these interactions as ignoring her deep need to offer care to her infant: “I think when my
coworkers were telling me that, like I, I understood they were saying it with love, but it was like,

‘Gosh! If you guys were on this side of it, you would see that there's no way.””

Lindsay also shared about staff encouraging her to rest, and the turmoil she experienced navigating the incongruence this message presented within her:

Then [the staff] tell you like, ‘you really should sleep.’ But you know you want to like be there, like, ‘Should we stay?’ And they're like, ‘No. You know, you should go home. You should sleep.’ And you know, set a timer and pump throughout the night. And just do that, you know, in the comfort of your home, which just felt like, really, I should do that? I, I don't know. It felt wrong.

Abby also identified her desire to care for her daughters while at times feeling overridden by the staff.

I would have some (nurses) that would come in. Just hook them up on their feeds, do their diaper changes do everything, and it would be in the middle of the night, and I would wake up and say, ‘No, I'll do it.’ And they're like, ‘Are you sure? This is our job, you know? You just need to get some sleep.’ And I’m like, ‘No, I wouldn't be getting sleep if they were at home, I’ll do it.

Women shared examples of being ignored as a valuable part of the mother-baby relationship. Brooke highlighted her deep need to be involved in care when her infant was sick.

She shared the challenge of staff decisions preventing her being able to hold her suffering infant:

Yeah, everything is happening so fast, and she's beyond consolation, like you can't… at that point, when she's so sick like they don't want you to touch her, and all she needs is me. Like, you know, like as mom, you're like all, all that they need is Mom right now. Like I know that I'm not going to solve it, but I know I'm gonna make it better.”

Brooke next shared about how she was eventually given permission by staff to hold her daughter reiterating the value of her maternal contribution.

so, she's just crying constantly, and um they needed to change her, and so I was able to pick her up, so they were able to change and slide things underneath, and when I picked her up she stopped crying, and so I only got to do that, for you know, a couple of minutes. But she stopped crying for those couple of minutes, and she knew that I was there with her.
Abby also highlighted wanting to be able to care for her twins, but finding that the staff were dismissive of her contributions, often giving priority to their schedules.

And then, you know, there were times where, if I didn't get there right in time for their cares, like I would call and say, ‘Hey! I'm on my way. Can you wait and hold off to feed them so I could try to latch them on me while they're getting their NG (nasogastric) Feed?’ You know, sometimes they would honor that, and sometimes they wouldn't. They would just be like ‘No, we need to stick to our schedule.’ And it, like that was super frustrating for me…Um, Because I would say, ‘Oh, I want to breastfeed I’m on my way. I'll be there in like fifteen minutes,’ and they would say, ‘Oh, we already started their feed.’

**Detached/Dismissive Staff Responses**

The subcategory of Detached/Dismissive Staff Responses addresses participants’ experiences of being overtly and blatantly dismissed by medical personnel. This subcategory differs from *Overriding the Mother Role* in the more deliberate intention and action taken by staff to communicate a message to the woman. Participants described two ways that staff responses emerged from their experiences. They explained that at times staff engaged in deliberate behaviors that sent the message of them feeling disconnected or even, that left women feeling burdensome to the staff. They also discussed their experiences with staff being black and white in their role as medical provider, and at times unwilling to engage in emotional support of the woman herself.

Jessie articulated feeling as though her needs were not only not a priority but rather, simply dismissed.

It was because the nurse like it was like when you first like, get up right, and so like um I didn't know how I'd feel. The nurse was like, I still didn't understand her. She was very kind of rude, passive, aggressive, was kind of like not (long pause) she didn't put me first like ‘Oh, let's bring you to meet your baby for the first time’. It was kind of like, ‘Well, if you want to go and meet your, or you know, go down to The NICU this, this would be the time to do it because I have to help you down there and have to stay with you and then bring you back’.
Here, participants discussed their experience and the feeling of staff being annoyed or bothered by their needs. There was a reported sense of staff recognizing the woman’s needs, but not attending to them. Several participants were willing to talk around these experiences, and did not articulate the experience boldly. Abby and Jessie, on the other hand, offered clear examples:

They kind of acted a little bit frustrated because she was hooked up to so much stuff, and it was so much work to try to get her out for me, to be able to hold her. So, I could tell that they were kind of like (making a disappointed/annoyed face) …Like, ‘Okay, yeah, just give us a few minutes’ type thing, and they had to call somebody to kind of help the respiratory therapist and stuff like that.

Jessie shared about how the first time meeting her baby was a negative experience due to the nurse’s detached approach. She shared, “But then it just felt super rushed because she was just kind of like (pause, making a face), ‘Okay we need to go back. You need to rest.’ I’m like, ‘No, I don't. don't tell me what to do!’”

Ellie similarly described an experience she had in which she felt unseen and disrespected by the nursing staff. She was left feeling as though she was overreacting emotionally.

I felt like the nurse, I remember when [Dr. X] had like rounded in the morning that was like our favorite neo that like I just love, and she, the nurse, had been taking care of [Tom], and you know she was kind of older, and she was like ‘Mom's worried about [Tom].’ It was just kind of in this way I don't even know, just yeah, just a little bit like kind of roll the eyes, you know? I felt just a little bit like you're not listening to me…. Yeah, it was kind of like. ‘Oh, she's worried again about some other thing.’

**Role Rigidity**

This property is about the ways that participants experienced staff thinking about their role as black and white. Participants articulated experiencing at times that the staff only engaged from their role as medical provider to the infant. In several examples women experienced staff placing rigid boundaries around what they were willing to do in response to the women’s expression of emotional distress and strain they were navigating due to their NICU experience. These rigid boundaries surfaced as an emotional handoff from doctors and nurses to family
members or as a mental health diagnosis which could be passed on by referral to mental health support and even at times to family members. Andrea shared her experience with feeling role rigidity surrounding staff’s commitment to the infants care rather than care for her. She stated, “But they are so overwhelmed and so busy, that I don’t, I mean it’s not really easy for them to, you know, spend much time with you and just make sure you are okay.”

**Emotional Handoff:** Participants describe brief responsiveness from staff, and attempts to avoid becoming too involved in the women’s mental well-being, passing off emotional responses as possible clinical diagnoses. For example, Lindsay articulated her experiences having a difficult staff interaction that led to crying for an extended period of time. She described multiple check-ins by medical personnel the following day, suggesting she may be struggling with depression.

I started to like just cry, you know, and I had a really hard time for that entire night. And I couldn't stop crying...The next day, of course I’m sure that it was probably reported and stuff, so my Doctor, those coming to check on me and the nurse, and everybody kept asking me like, ‘Do you think you could be depressed?’...And I was like, ‘Well, I feel like I was just really reacting to like this situation that I was in, you know... I just felt like, It's okay, that I'm just really disappointed, and sad and overwhelmed. And all these things, but because of that, I was ‘referred’ (applies hand quotes), and they wanted to check up on me... But the counselor that they had to put me on her radar, and she like checked in with me by phone.

Andrea also shared an emotional moment when staff responded reactively. Instead of joining her, or attempting to understand her distress, she reported feeling passed off. She shared her experience being resourced out to other possible support options. Andrea described this as unsupportive despite good intentions:

...So, like this poor lactation consultant and RN was like, what is wrong with this, like, ‘Are you like mentally okay right now?’ And I think she was like ‘Oooo this is not good.’ And, then they are like, ‘Where is your husband?’ Like, ‘Do you want us to call your husband for you?’ And I was just like ‘No, my baby, the alarm was going off and it was just really overwhelming, and I was just crying.’
Infrastructure Collapse

The women in this study articulated a distinct experience of their personal needs going unmet by the system. Participants shared about how the infrastructure of the healthcare system bypassed their needs be it with physical barriers or the organizational structures of the system. One example of this was one hospital’s housing arrangements for mothers relocated to their NICU. Jessie was transferred to a larger hospital away from her home shared this about her housing option:

Because I had Medicaid... they helped us with a hotel. A horrible hotel. Like a sketchy one. I don't know if you've ever been to [Hospital]. Oh, there was like this like dingy, dingy, horrible hotel. That's right across from the hospital, and that's where they, that's where they like contract and put families in.

She discussed feeling physically unsafe in the accommodation: “And then the hotel we were in, that was super sketchy (laughter). Um. And so, our safety was a bit of a concern.” Organizational structures of the healthcare system included staffing choices, ratios, and the hospital’s operating protocols and policies. Jessie articulated her general sense of the NICU not being set up for the mother’s comfort:

And then I think just the physical space. It wasn't comfortable by any means, like they don't...although they want it to be accessible for families to be able to stay in there and to be there with a baby it's, it's not. Or the room that we had wasn't. I don't feel like.

Physical

This property refers to breakdowns in physical infrastructure that created barriers to basic care of the women. These barriers revealed a lack of orientation and understanding to the physical needs of women. For example, Abby described a lack of knowledge about a shower in the NICU. Due to this omission, she was unable to engage in basic hygiene tasks at the hospital while staying near her infant:
I didn't know for the first week and a half that there was a shower up there that I could have used, and nobody told me. Nobody brought me a towel. Nobody brought me toiletries, nothing, and so I’m running back and forth from home. I didn't have time to shower. So, . . . then I ended up bleeding all through my clothes and stuff one time, and I told a nurse I was like, ‘Do you guys have any pads? Do you have anything?’ And then she's like, ‘Oh, yeah, let me go grab you some stuff.’ And then I was like, ‘Well, I'm gonna have to run home and get clothes.’ And she's like ‘Well, there's a shower up here.’ And I was like (gasp), ‘there's a shower?’

Jessie described an absence of care due to infrastructure challenges when discussing her need to pump, access her infant’s car seat, and do laundry. Because she had been transported to a medical system over 100 miles away from her hometown, she was unable to access her belongings or home during the entirety of her NICU stay.

And I’m like, well, I don't have a pump because that hasn't come in yet, and I can't take one from the hospital, you know, unless I go there or stay there…. All these like random things that we needed, and that they're like, ‘Oh, yeah, you're getting released,’ and . . . we don't, and he needs to do the car seat test. So, it was just always on the… just coming up with solutions.

Jessie also encountered a barrier getting her basic needs for clothing. “It was always like, oh, well, I'm running out of clothes. So, I just need to go buy socks because our, the laundry machine is broken in the NICU. So, we can’t wash our clothes.”

Andrea identified that even the layout of the hospital design created difficulty gaining access to her infant; the two wings of labor and delivery and the NICU were so far apart. She stated: “I mean, I think it's probably this way with many hospitals, but you know, the NICU is not very close to the side of labor and delivery, especially where I was. I was on like the, the furthest side all the way down at the end of the last row.”

Many participants also referred to the emotional and physical discomfort of open bay room assignments. Open bay rooms are larger rooms which house multiple infants, sometimes pods of 8-10 babies, with separation by curtains. Andrea discussed in detail her discomfort and
the emotional toll she experienced occupying an open bay room, having little privacy for herself as well as difficulty attempting to respect the privacy of patients and parents around her:

The shared room was very stressful...I mean, because it is a big open room and there's just a curtain, more or less, and we had some, we were really advocating for our own room. We just got there, and a baby and a parent and, it was I think, a caseworker’s situation. Um, and it just like made us feel very uncomfortable anytime the mom was there. .... And just her conversations, like out loud, and made us feel super uncomfortable. And it's funny because my husband and I feel like we're not, I mean, we'll speak up in situations, but for the most part, we’re like, ‘Okay, it’s fine. We’ll just make it work.’ We’re pretty laid back for the most part. But it got to the point where I looked at the nurse who was a mutual friend or had mutual friends, I just looked at her one day and she was like, ‘We’re gonna really try to get you your own room.’ And she's like, ‘I'm advocating for you’... And like, you know, you're not really...I didn't really have to have any hard conversations about [Sam's] care. But I think listening to other people's conversations kind of made me, not made me uncomfortable, but I don't want to hear about this caseworker situation and all of the drama that's happening with this family. I don't want to have to hear this...And just the conversations, and then hearing, you know, other parents talking about their, I mean, they're getting into arguments with like the nutrition and nutritionist and just sort of just that whole piece. I feel like kind of just added to the stress... so that shared space was definitely really challenging. Yeah, for sure.

Andrea, too shared in the physical discomfort of the open bay: “And so that was hard because I'm basically sitting in a chair like this (cramped over), more or less with a stool, and like taking naps, you know, sitting up with like, my neck kinked, like trying to pump in there too.”

**Staff Challenges**

Infrastructure collapse was also evident in participant reports about their experiences with staffing challenges. These challenges were due to low numbers of staff in departments and frequent staff changes. In some cases, the lack of nursing staff was due to absences because of COVID (WHO, 2020). Ellie describes how breastfeeding was unsupported due to infrastructure barriers and staffing challenges.

I felt like the Labor nurses, that was like, that (pumping) just was not really a priority, you know...And the NICU nurses, bless them, but like they're just not, they're not lactation consultants, you know. It just was, yeah, it just ended up, not really working for
us…and you know just even simple things like helping with breastfeeding when there is literally not even a lactation consultant on call in the hospital, that would have been huge.

Later, Ellie again identified the ways she experienced COVID impacts in the staffing realm, “I mean, that's what was hard, too. It kind of was the perfect storm. He was born a week after our hospital had enforced the vaccine mandate…they lost a ton of NICU nurses. So they had [to hire travelling nurses] travelers.”

Abby described her distress of listening to multiple babies crying for long periods of time due to high census and strain on the nursing staff. She shared, “and then even going up there like I would hear other babies crying and crying and crying, and nobody’s going in and tending to them, and I would have to be like, go and get a nurse and say, ‘this baby’s been crying’ like, how come nobody’s in there holding them?’”

Jessie also identified an experience when staffing presented a lack of continuity due to shift changes and shortages: “And so we would like get used to [nurses], and then they'd be gone the next day, or within that shift. And then they're like, ‘Oh, well, you guys will probably be gone by the time I come back.’” The medical system Jessie was in was also set up for training, resulting in added difficulty building rapport given more staff inconsistency. This inconsistent care added frustration to her experience in the NICU.

And so, and then they were in this weird, rotating thing because they were doing shifts between the birthing center, but then also the NICU. So, there was like new nurses, from like the college coming in too. So, yeah, it was, it was kind of (pause) hard.

Abby discussed how staff shortages were difficult to navigate, and also deeply impacted her as she ignored her own needs to avoid adding pressure to the staff.

It's not fair for the nurses, because you know they're doing as much as they can, and they're being torn all different directions. I can tell some of the nurses were struggling, and we had a lot of traveling nurses because we were so short staffed because of all the COVID stuff. So I could tell, a lot of them were like overworked overtired and under-
appreciated. And it just made it that much harder for me too, because I felt like I didn't want to ask them for anything. I didn't want to ask for lunch. I didn't want to ask for extra bottles. I didn't want to ask for, you know, like to put my milk in the fridge after I pumped, like I didn't want to ask for extra stuff.

Frustration with System Communication

This subcategory focuses on the way the women are forgotten in the medical system’s communication. The absence or brevity of communication created frustration for women within the NICU. This frustration for women arose in several different aspects. Properties of this subcategory include NICU Prep while Pregnant and Communication of Treatment Plans and Treatment Changes. Women shared about experiencing the lack of communication about the possibility of entering the NICU during their pregnancy. They further described their experiences with changes to treatment plans for their infants without being informed.

NICU Prep while Pregnant

Communication about the NICU is lacking or sparse during women’s pregnancies. Participants identified improvements to communication that could have better prepared them for the NICU. Ellie discussed very briefly interacting with a neonatologist while being prepped for surgery. She highlighted the transience of the conversation while also attempting to understand the suddenness the medical staff must also be navigating. She noted that it likely would have been much different had more time been available for a consultation. She shared:

I think we met with a neonatologist, for, you know very briefly while they were prepping me and everything...yeah. And originally I was going to meet with the neo the next day, and you know I think it would have been a longer conversation.

Jessie shared her frustration feeling unaware that the NICU was even a possible situation that she could face:

I think one thing was being not told anything in regards to like, you know, when you're doing your prenatal care, nobody says like there is always a chance [of receiving NICU
care]. You could have your baby early, and so just like not knowing anything, about the NICU, you know.

And later adding:

Yeah, And I think it could just be a conversation of like, although this is not something that we're perceiving might happen, I think it's very important that you guys should be prepared in case anything ever becomes an issue or concern. And these are the things you could know.

*Communication of Treatment Plans and Treatment Changes*

Women also experienced frustration when they were not informed or consulted on treatment plans, changes, or progress of their infants. For Jessie, this was evident as she described the lack of communication about the emergency birth of her son, and being uninformed about the seriousness of the situation as she was flown to the hospital. She stated, “So they were just like, ‘When we land, you’re probably gonna get you evaluated and checked, and you might have your baby.’ I was like, ‘What?! What?’ Nobody told me this. I thought I was just getting, like, you know, like monitored.”

Abby shared a story about her twins being moved from their initial room to an extension NICU due to a high census of babies.

On the fourth day they moved them up to the [NICU] nursery, and it wasn’t because they were doing great. It was because our NICU was overcrowded and they didn’t have room for more babies, that they needed. And so, they said, ‘Well yours are the ones that are least critical right now. If we had the space, we would have kept them down here longer, but we don’t, so we just need to move them up there.’

Abby recounted her experience with the medical system ignoring communications with her about the move until she experienced the deeply distressing moments of walking into an empty room that originally housed her daughters.

Well, I didn't even know that…I went to go see them. The nurse took me in there to go see them, and they weren't in there. I started panicking and freaking out and crying, and I’m like, ‘Where are my babies?’ Yeah, and nobody knew where they were. Until they were like asking around, asking around. And I’m like, ‘Yeah, this is where my kids were.
They were right here in this corner. They're no longer here.’ Then they're like ‘Oh, hold on, let's find out! Hold on,’ and I’m just like what do you mean find out? Like... So, I thought like something happened to them, and nobody told me. You know that was my first like gut feeling... So then they're like, ‘Oh, no, no, no, they're upstairs.’ So, then I was like, okay (exasperated).

Additional communication frustration presented in a lack of clarity about the length of stay their infants would have in the NICU. Lindsay described becoming deeply frustrated with the uncertainty surrounding her son’s treatment timeline. Although she can understand the absence of information, she remained clear about the challenge it presented and the need for some level of communication:

I get that, I get why they don't ever want to tell you. I get why. I totally understand why they don't want to say exactly like when the baby can come home, because so many things could change. Or you know there's just all of that, but I REALLY wanted (clapping hands in frustration) somebody to like give me a date or something. Like I wanted to know how long we had to be doing this. I knew that that was impossible. And really frustrating.

The Juggling Act

The women in this study identified many challenges that they faced during their experience of having an infant in the NICU. The challenges vary from logistical and practical barriers such as scheduling and work and finances, to the women’s feelings and experiences of being unable to access their infants. The women described The Juggling Act as the ways in which they managed the many aspects and roles - “balls in the air” they were handed upon entering with their infant into the NICU. Participants identified this experience of managing as pressure-filled, while at the same time also finding comfort in the ‘doing’ and routine. As the women described their experiences it became clear that the juggling act is about the external management of the experience of having an infant in the NICU. They described the subcategory of Logistical Tasks that needed managing including their physical recovery, finances, work and scheduling. They also described part of the juggling act as needing to manage, and hold at bay,
their emotional experiences. These pieces of the juggling act surfaced as the Mental and Emotional Tasks, another subcategory, that women placed their external focus on, rather than looking inward at their own emotional experiences. Participants described experiences of being physically alone much of the day, being separated from their infants, and even enduring their emotional experiences of their infant’s nonlinear medical progress. Although the tasks they faced were filled with emotional decisions and strain, participants placed their focus outward. They placed an emphasis on doing and managing the tasks before them in order to be present for their infants. Subcategories of The Juggling Act are Logistical Tasks and Mental and Emotional Tasks. Properties of Logistical Tasks include: Self-Sacrifice, Work and Finances, and high-pressured Schedules. Properties of Mental and Emotional Tasks include: Maintaining Proximity to Infant, Alone, and Nonlinear Medical Progress.

Logistical Tasks

Women identified aspects of their life which they felt they had to keep engaging with despite their desire to slow down and just be present in the NICU. They shared about sacrificing their own needs for their infants needs including sleep, eating and movement, and even their physical recovery in the subcategory Self-Sacrifice. Women also described having to continue navigating Work and Finances, and high-pressured Schedules. Simultaneously, The Juggling Act works to steer women away from the emotionally laden internal struggle of having their infant being placed in the NICU. Brooke talked about addressing each moment separately in order to keep going in all that was expected of her. She shared,

I mean, it was kind of um, kind of one of those things where I just had to…It was one moment at a time. You know I had to compartmentalize a little bit, because I needed to make sure that (pause) I was able to be there for [[Josie]] and be a support for her and… But I also needed to make sure that I was a mom for my son, and that I was a wife for my husband, and that I was able to (trails off) …
Several of the participants described this process as “doing it all” and needing to keep up, while others described it as a sense of being unable to juggle all that was coming at them. Brooke identified the struggle of being pulled among many roles. She stated “trying to juggle everything right. I think the most challenging thing was trying to juggle like I said, being a mom to this little nugget and to sister and being a wife.” Ellie stated the difficulty of having so many balls in the air during her experience in the NICU, “I just couldn't figure out how to juggle it all.”

All the women in the study engaged in the juggling act. Andrea described the challenges she faced of recovering from her C-section, pumping, and still feeling pressure to keep juggling. She shared, “And so much goes into postpartum too, you also don’t feel great after a C-section and your boobs hurt and you are constantly pumping and you just, that whole piece too of, just remember you have all these things to do still, as a mom, and that’s bizarre.”

As the women described their experiences of juggling, noticeable attempts were made to stay busy as a way of managing the proximity with which the women came to their emotional distress surrounding the events of the NICU. The juggling act is the last stop before experiencing an inward, down turning spiral that results in low mood, negative and hurtful internal messaging and emotional turmoil. In many ways, the juggling act served as an avoidance strategy temporarily preventing women from entering the emotional trenches of the NICU experience. Lindsay shared her experience of engaging the juggle, and feeling a sense of success in “doing”:

Because I was like juggling so much that it, that it, you know (pause). I think I was, you know, still somewhat taking care of myself and managing to do what needed to be done. And take care of [Sage], yeah, and pump. It was like, really I'm doing all my jobs. The things that I can do.

*Self-Sacrifice*
This subcategory of “The Juggling Act” is defined by women’s attempts to ignore their own needs by choosing to put their infants first. Self-sacrifice served women as a maintenance tactic. That is, it allowed woman to push their own needs aside to “keep going.” By engaging in this outward going and doing, women were able to briefly avoid the downward spiral that was awaiting them, and perform for the benefit of others, especially their infants. When the women of this study were faced with the tension between their own needs and that of their infant, the result was often described as the participants foregoing their own needs. Several of the participants explained this as a natural process, while others described it as a preoccupation with their infant. Whatever the reason, the women were able to articulate that their needs no longer felt prominent. Although the lack of priority felt accurate, women reported that they understood the necessity of attempting to take care of themselves. Participants shared that self-sacrifice was often driven by their need to continue caring for or gain access to their infants, in some cases even at the expense of their own physical recovery. Andrea stated it most succinctly: “And then obviously the baby was my Number One concern… But yea, you just don’t even, you don’t put yourself first anymore.”

Ellie identified her experience of self-sacrifice as an instinctual part of becoming a mom. She explained,

There’s no way I can even focus on like my pain meds and the fact that my blood pressure is still high. That is not, it just wasn't even on my radar, you know. And I think that was just, I don't know, just adrenaline of him being born, and just the new mom instincts of being concerned with him. And yeah, it was like I took a back seat.

She continued, stating, “I just didn't really, it didn't sink in until much later. You know how important it really was to still take care of myself so that I could be there for him (crying). That that was really hard to juggle for sure.” She also discussed her loss of appetite and a
simultaneous experience of pressure to eat in order to be able to provide milk for her baby. She reported

And I also, I didn't know how to take care of myself as well... And so, it was like I just, I wasn't as hungry. Which I realize now was probably just more of the actual anxiety and depression, but I had never felt like that. I almost felt nauseous at the thought of eating. And so then, and I wasn’t eating or drinking as much, so then I was worried about my milk production it just was kind of this, you know, never ending cycle.

Abby discussed how her lack of time and need to be with her infants at the hospital took priority over her basic needs. She shared, “Well, and it's just like we're postpartum. We're bleeding all over the place, and we're so gross and when do we get the time to take a shower? And so, it's like I’m running back and forth from home. I didn't have time to like shower.”

Brooke also highlighted her attempts to care for herself, and the simultaneous result of sacrificing herself to be with her baby in the NICU. She said,

And I would (take care of myself) occasionally...Yeah, yeah. And it was, you know, one of those things where it was pretty obvious that I wasn't taking care of myself. Like not eating and not drinking enough water. And really the only reason why I took care of myself as far as even eating and drinking is because I knew I needed to provide milk...But you know, no sleep, and not doing, not working out, not doing things that I know make me happy and make me feel good.

She further explained the emotional guilt she felt “And you know, but you feel so guilty doing those kinds of things [self-care], and what if something happens?” Jessie described that she made a more deliberate choice to put her son’s wellness first by ignoring her own. She stated: “And so I was like whatever that means for me, I’ll do what I can. Because, even like my pain management. I mean, I was in pain. I'm sure I was. But I didn't care. I was just like determined to be better.”

**Ignoring physical needs to care for infant.** Several of the participants also described juggling and managing their own physical recovery from C-sections and medical complications. This part of the juggling act focused primarily on the women wanting and needing to urgently be
with their infants when separation occurred immediately after birth. Ellie described her
experience managing her own physical recovery while also feeling the emotional pull to get to
her son.

I had to wait for the sensation to come back my legs before I could get in the wheelchair
and go see him and that was like torture. Yes, I kept saying to my mom, ‘Am I wiggling
my toes now?’ And she'd look (shaking her head), and she'd be like ‘I'm sorry.’ And it's
such a weird sensation because you feel like you are, but you're looking at them, and
they're not moving…So, I think it felt like it was only like a couple of hours in the hustle
and bustle of things, but I remember one time going back, and looking at the photos of
when we could finally do skin to skin, and I think that was one thirty in the morning. So,
you know, it was almost four hours before I got to see him.

She later shared about how the medication she was on left her feeling unlike herself and unable
to function how she normally might. She went on to further share how her need to be close to her
son precluded her concern of personal recovery.

So, it was hard because the magnesium really like…Ugh, just like physically. I did not
feel well on that (laughter).…Yeah, I just I felt so slow like, even when people would like
talk to me, and I would respond like I felt like it was just everything was slowed down. I
was so thirsty, (pause) but the whole time I really was just so preoccupied with him. And
how was he doing and…that, I don’t… Then I never. I don’t know, I don’t remember it being
super painful, or worried about my own physical recovery at all (voice quivers).

Abby shared that she forced her body to walk in order to get to her daughters. She shared,

Yeah, yeah. And then they told [Medical staff] me that I could not go see them [twins]
until I, my meds, wore off, and I was able to get up and stand up and get into a
wheelchair… So that took a few hours, and honestly, my legs were still numb, but I
forced myself and said, “Oh no, I can do it” …Yeah. So, then I could go and see them.

Lindsay also referenced her challenges with needing to juggle her own physical recovery
and being with her son. She shared a story about her need to care for her son during a specific
care time and working to manage the challenge that her body presented after having had a C-
section. She shared,

Wanting to do the things that you can that you're allowed to do at the times where we
could change his diaper, and I really wanted to be able to do those things, and I was
Andrea articulated being quite ill after delivery and becoming violently ill while visiting her infant. Due to vomiting she was unable to stay in the room during her visit with her son.

I look at my Nurse. I'm like, “you have to wheel me out of here, right now. I'm gonna start throwing up.” everything just, I'm not a, I do not throw up. And so, it was very, that whole piece was super overwhelming too. And of course, it was just because the anti-nausea medication that they were giving me through the IV wasn't working so they had to give me a different one eventually, and throwing up after a C section is the worst. It was the worst pain ever. You have nothing in your system anyways. So, it's like I'm eating an ice chip and then within 15 minutes, I'm throwing up my ice chip (laughter) and so yeah. Obviously (slows down speech) I did not, I didn't feel very good, so they brought me back to my room. And of course, all you want to do is be with your baby and you really can't after a C-section.

**Work & Finances**

Several of the participants identified needing to juggle the financial and work aspects of being in the NICU. This was described in terms of the impacts on income, the potential cost of having an infant in the NICU, and in terms of the time away from work that the women had to navigate. Abby described a challenging part of her experience when asked in first round interviews.

Interviewer: How about other areas that you as a woman were impacted by having an infant in the NICU?

Abby: Financially, extremely financially, because it's like if I didn't own my own business, I wouldn't have been able to be up there with them the way I was.

She continued on by describing the benefit of being self-employed and being able to take time away from work. Abby simultaneously acknowledged the financial strain this absence from work placed on her.

So, I missed a lot of work, granted I run my own business, so I pay myself, but I, the financial aspect of it was still super hard, because I’m not there, and so I’m not able to do what I need to do when I’m here. So, I had to pay somebody else to cover me while I was out. And so that took money away from me and from my family and my kids. And, I lived thirty minutes away from the NICU, so I would have to drive thirty minutes there...
and then thirty minutes home, and I have a SUV. And it was over probably eight hundred to one thousand dollars a month just on gas...So Yeah, financially, it was extremely hard.

Ellie articulated her gratitude for financial security while acknowledging what it would have meant without having a savings that could be used for this event, “I mean, we were pretty fortunate that, financially, we were gonna be okay. We had a good amount of savings, so that, thank God, you know, was not like an added burden.” Andrea highlighted the paradox that mothers often face with the financial component of having an infant placed in the NICU. She noted a sense of gratitude for insurance support due to her infant being so early and weighing below a certain number of grams. The cost of being small enough to qualify for state insurance also meant that her daughter was really sick. She shared, “I think you know, because she was so early, we, she is a Medicaid baby. Like we were very, very blessed because she was a micro preemie. We didn't see a bill. You know we didn't have a worry with that, Thank God.” Andrea also discussed the repercussions of the financial strain on her family as she had to step away from work in order to be in the NICU with her daughter. She shared, “Obviously [my husband] had more pressure on him financially than I did since I wasn't working, but we were still getting paid thankfully, through a sick bank at my school.” Jessie felt financial pressure being in a NICU away from her hometown: “Another thing is like the financial burden right, of being away from home because we weren't in home we were not home .... And then, so then, having to pay out of pocket for like meals.”

Schedules

All of the participants of this study discussed that one of the major components they had to juggle was an overly busy schedule in order to take care of all of their responsibilities and still be able to spend time with their NICU infants. Although the participants of this study identified
feeling strain over the busyness several of them simultaneously reported finding comfort in the routine, as it offered some security and a sense of “doing.” Ellie discussed the overflowing nature of her schedule during her NICU stay. In this example she highlighted both the pressure and comfort of the routine.

So, I would, in the evening my husband and I would usually leave like about nine or ten or something, and come back and sleep, and then, I would still be setting my alarm for every three hours to get up and pump. Then [husband] was off that first week that I had him when we were in the hospital, but he went back to work after that, and then in the morning I would get ready and go to the hospital, and pretty much be there all day. Then I would come home later in the afternoon. We would have dinner at home, get ready, go back to the hospital, and honestly, as hard as it was, . . ., I actually, mentally and emotionally, for some reason, I kind of did better with the routine.

Abby, Brooke, and Lindsay had children at home when their infant was placed in the NICU. They had to navigate parenting their older children and balancing their time between both children. Abby described the rigid schedule she followed to make sure her older children were cared for and prepared for their days, before heading to the hospital for the remainder of the day.

I would get them ready, take them to school and then spend all day at the NICU, and then go pick them up from school and go home and spend the evening with them. Yeah, and then my mom would spend the night with the boys, and I would spend the night with the babies. I would go back to the NICU and spend the night with them, and then I would get up super early in the morning, drive home, get the boys ready for school with my mom, take them to school, and then I would do it all over again every single day (listing rapidly the routine).

Abby, also shared about the pressure in the midst of an already busy schedule to fit in the necessary requirements for her kids at home while single parenting.

And then, even just being able to do everything I needed to do to support my other kids. Like being able to just even cook them dinner, or help them with homework, or, you know, make sure that they had a good Christmas. All of that stuff was all unexpected.

Relatedly, Brooke identified the need to keep routine or her son at home while also being at the NICU as much as possible. She said,
So, I was there until, because I treated NICU kind of like a job, right? Because we live in small town and [Parker (first child)] is a little guy, so I still kind of want to make sure his routine is still the same. So I would take him to daycare, and I would head to NICU and then I’d be there until five normally, and then I would come home.

Lindsay also shared about how the routine, though rigid, allowed her the opportunity to feel as though she was contributing to both of her sons.

But then I felt like we kind of fell into sort of a rhythm for a few weeks, you know, because I was just like pumping every two hours, and then we would drive from our house to the hospital. We’re doing that about four times a day, you know, to see him. Yeah, because there were times where he could, you know where we could change his diaper, and then our rounds when we would be able to talk to the doctor. So we always wanted to be there for those times. But again, really needing to also see my other son, and take care of [Sage] and um... But so that was just, you know. It was, in a way just really busy, because, I pumping every two hours. I’m trying to sleep a little bit. I’m trying to get back and forth to the NICU.... and in a way, I think that that was a little bit helpful, you know, focusing on all of that and being so busy with it.

Andrea didn’t have children at home and identified that the entirety of her days were spent in the NICU to stay close to her son. She stated, “And then I didn't want to be at home because I didn't want to be away from [Sam]. And so, then I was, you know, spending 16 to 18 hours a day, basically, in the NICU.” Jessie also relayed her commitment to spend her day in the NICU with her son. She shared, “ah, um (thinking) It felt like I was always there [at hospital] like I just refused to leave.” Away from home, Jessie only used her hotel accommodations for sleeping purposes. She continued sharing her experience of using her day to be with her son in the NICU. She stated,

So that was all I needed it for (hotel room) um, because every other time we were just staying in the room with him all day. We'd wake up early in the morning to make it there for breakfast and rounds to hear about how his progress was, and what we could do to get him out of there. Pretty crazy.

Mental and Emotional Tasks
Participants described the multiple mental and emotional tasks they were faced with juggling and managing. These “balls in the air” were less about doing and more about the emotional challenges they faced. The women in this study described remaining external in their thinking and continuing to show up and “get through” their NICU experiences. Properties of this subcategory include; Maintaining Proximity to Infant; Here, women worked to manage their experiences of being separated from their infant and searched for ways to remain close. Another property of this subcategory is the mental challenge of being Alone. Women described grueling days of hours alone in their NICU rooms and managing their emotional and mental experience of this. Finally, women articulated their experience of juggling their infants nonlinear medical progress, placing a focus externally on their infant once again, rather than their own internal experiences.

**Maintaining Proximity to Infant**

A major component of what the women of this study described was their experience of juggling being separated from their infants and working to maintain proximity to their infants. Participants emotional experience of separation was described in many ways including: fear of being unknown or detached, the pain of being away from their infant, and a sense of loss of proximity to their infants. While the emotional distress of being separated from their infants was taxing, this aspect of their experience was about the external management of their separation rather than the internal emotional experience that the Deep Dark Battle held. This management acted as the precursor to the Deep Dark Battle, the point when women move from external management into internal processing.

Ellie shared her experience of staying in the hospital herself in order to be close to her son. She stated, “So I stayed. I could stay like four nights five days. I stayed the entire week, just
to be, you know, closer proximity to him.” She shared about her experience of working to remain close to her son and the emotional strain she had to manage as she had to return home each night, leaving her son in the hospital.

I couldn't wait for him to be moved upstairs to the [NICU] nursery. That felt like just a big, you know, to do, and then I could finally room in with him. But it was probably, it was like two and a half weeks before he could go upstairs, and so, that was rough, because, you know, I would be there all day long. And then my husband and I would visit in the evening after he got off work. But then we would have to go home.

**Fear of being unknown/detached.** Participants expressed deep worry and sorrow about their bond with their infants due to not having initial bonding moments or easy access to connection with their infants. Women expressed a sense of having to juggle this emotional task, and finding ways to remain focused on continuing to move through the challenges they faced. Abby articulated reaching out in order to address and support herself regarding her fear of not bonding with her daughters, “And I just told her (social worker) I already feel like I’m getting postpartum depression. I already feel like I’m having a really hard time because I don’t feel like I’m able to bond with my babies.” Abby shared later on about her continued concern about bonding, the longer her daughters were in the NICU, “and I wanted that connection and that bond that I felt like I wasn't getting by not being able to bring them home.” Brooke discussed her reason for being present for nearly every day of her infant’s 110 days in the NICU. She shared,

Just because even if I was only in for a little bit I would make sure I came in every day because I wanted, I was like, what if she doesn't know me, you know’ because this isn't like a normal pregnancy. What if she doesn't know me? I want her to know my voice, you know, just like normal.

**Pain of being away from infant.** As the participants of this study discussed being separated from their infant for many reasons, descriptions of pain and suffering of the experience emerged. Women described factors such as the infants need for medical intervention, their own discharge from the hospital, particularly having to leave their infants behind, and the juggling of
other priorities which required attention, as reasons for experiencing suffering. Women described the intense pain they endured of having to be away from their infant while also figuring out ways to juggle this pain and continue on. Despite their suffering, the participants all reported being able to manage the suffering and remaining present in the tasks before them. Ellie shared it most clearly when she reported, “I had to wait for the sensation to come back my legs before I could get in the wheelchair and go see him and that was like torture.” Andrea discussed the moment she had to leave her infant in the hospital. She expressed, “and so I think, leaving your baby in the NICU for the first time and going home without them was probably the most traumatizing thing I've ever gone through. I mean, the car ride home I was just bawling hysterically.” Lindsay also discussed the intense feeling she had upon being discharged and being unable to leave the hospital with her son, “I had this really, really hard feeling when I was gonna be discharged to like, leave the hospital without [Seamus], you know?”

**Alone**

Another part of the Juggling Act that the participants of this study described was the difficulty of being alone for many hours each day. Women described being unable to have others into the NICU due to policy and increased restrictions due to the COVID pandemic. This lack of social interaction presented another mental challenge, or “ball” in the Juggling Act, the women had to navigate. Some discussed feeling added pressure to manage logistics while others described the mental tax of being alone. In the Juggling Act, participants articulated being alone as an external experience that they navigated, different from the emotional loneliness they experienced during their internal downward spiral. Jessie described this being alone starting at the very beginning of the NICU journey, immediately after her son was born. She shared, “I told
his dad to go with him to the NICU, and then I got left there (laughter), and then brought to my room. Then I yeah… I just got sent to my room.”

**On my own.** Several of the participants described feeling on their own in the process of being in the NICU. Abby and Lindsay gave clear examples of this. Abby described being a single mom as a major barrier. She expressed deep worry about having to endure the NICU while having kids at home on her own. Again, an example of feeling pressure in the Juggling Act to focus on ‘doing’, rather than feeling. She said,

> so that right there was just a major major, um (pause) obstacle that I had to try to overcome, doing this without the safety and security of having a man there… I’m a single mom, I have to do this. I have to get my kids to school still, I have to, you know…And I’m doing it by myself. I don’t have a partner.

She continued expressing her distress, “How am I going to do it by myself? And then how am I going to do it with two? How am I going to do it now with two in the NICU?” Lindsay also described feelings of being on her own in the process of having an infant in the NICU. She discussed the turmoil she felt that none of her family had met her son. She shared, “Nobody (emphasized) was allowed, so you know even my sister hadn't met him, and he was a month old.”

**Physical space.** Participants described being physically alone and this physical aloneness adding a mental challenge to their already full load. As the women endured isolation and being alone, they simultaneously began to experience a sense of low mood which led to a later sense of loneliness. Ellie described, “So, and it just, I think, when I was rooming in it, it was a little bit isolating during the day…I just was in that room just too much without going outside.” Her statement of “too much” implies that the result of this isolation had negative consequences to her. Andrea also described countless hours alone and a sense that it was not positive for her personal wellbeing. She shared, “And so then I basically just sat in a dark room all day long.
Alone! And, you know, my husband's working. Nurses come in, but they're so busy as it is...And so yeah, that was the hardest part was just being alone, alllll day long."

**COVID as a complication.** The COVID-19 pandemic was at its height during many of these participants' entry into the NICU. Due to necessary precautions and mandates, participants were unable to have more than their spouse or a single support person into the NICU. COVID also presented complications for which the woman had to juggle: for example, an inability to meet in support groups or with other women who also had infants in the NICU. These policies magnified the women’s sense of isolation and amplified their juggling. Abby shared her experience of not being allowed to have the support she needed during her delivery and her infants’ admittance to the NICU. She stated,

> And then, all of this because of COVID. And so, I couldn't have any other visitors come in. Nobody was allowed to come in. I had to have the same two people, which was extremely frustrating, because my mom wanted to come, and she couldn't make it in time. So, my aunt was there with me, and like one of my really good friends, and then my aunt wasn't as supportive as I needed her to be, but then she was one of my support persons who could come.

Similarly, Jessie identified the complications of COVID more during the pregnancy than her time during the NICU. She shared about how her partner was unable to attend appointments with her and it wasn’t until her medical complications were serious that he was allowed in. She shared, “[Oscar’s] Dad got um, that was like his first time in the room because of COVID, so he didn't really get to ever be in an appointment with me.” Andrea also shared about the ways COVID negatively impacted her pregnancy journey by increasing her fear and stress which led her to be isolated from others quite often.

> I was (wide-eyed) I did not want to get COVID. When I was pregnant and you know, risk being completely isolated and then not being able to see [Sam]. So, I basically didn't see anyone except for my husband for probably the last like five weeks of my pregnancy just to make sure you know, I didn't even go to the grocery stores. I was doing grocery delivery and I just wanted to be as safe as possible, because I didn't want to be isolated. I
couldn't even imagine testing positive for COVID and then not being able to go to the NICU to see [Sam]. I mean, that would have been, I think, a devastating experience.

Andrea shared about only being able to have her husband into the NICU. She said, “And of course, it was COVID times too, and so you know, obviously it's just my husband and I”. She continued, sharing about how COVID precautions prevented her from being able to engage with others while in the NICU. She shared, “I feel like my experience would have been a little bit different if it wasn't during COVID. You couldn't really talk to any parents while you were there. You're trying to keep your distance from people, it was just this weird time in history.” As Andrea continued to share her thoughts about the impacts of COVID on her experience in the NICU, she was curious about how her experience could have been different without COVID precautions. She shared, “And I'd be so curious to see what other people's experiences were maybe before COVID, Because I don't know if it would really be, if it would be similar. I mean, I'm sure it would be similar in ways.” And again, later in the interview “Yeah. Just also being crazy about you know, germs and also all that too. So maybe, pre COVID probably would have been different.” Ellie expressed her biggest challenge with COVID complications was that she was unable to have her mom with her during her delivery, her own hospital stay, or during the time that her infant was in the NICU. This lack of support magnified her struggle and loneliness.

I mean, selfishly obviously, there's nothing you can do about a pandemic. But, I just feel like it would have made such a difference to have my mom be able to be there. We're just super close. She's like my best friend, and you know just even simple things like helping with breastfeeding when there is literally not even lactation consultant on call in the hospital, would have been huge. I feel like to have just that support in person. Obviously, we talked on the phone and stuff, but just not quite the same. And (pause) I don't know it's hard.

**Nonlinear Medical Progress**

All of the participants identified the emotional and mental challenges they faced due to their infants’ rapid changes in medical progress. They described experiences in which their child
would progress towards wellness and then would take a rapid turn in the other direction. Participants described the shift as often being dramatic and surprising, and ultimately very frustrating. Participants vacillated between telling the traumatic and negative experiences they had, followed by the times when they felt their infants were successful or “doing well”. The women expressed this as a large part of the juggling process that kept them focused on the baby rather than their own internal experiences. By focusing on their infant’s health, women were able to relocate their emotional energy to the medical facts surrounding their babies, rather than becoming entrenched in their own emotions of the experiences.

**Pregnancy.** For many of the participants the experience of infants’ nonlinear medical process began during pregnancy. Brooke’s pregnancy journey with her infant was marked with many twists and turns which she shared openly about. Her story highlighted the experience of nonlinear progression to delivery. Brooke described, “We did the test to see if there was amniotic fluid, and there was, and so they transferred me into [Hospital]. And it was kind of one of those things, you know, ‘expect the worst. Know that this is likely not going to be viable.’ But ‘hope for the best…’ After she first learned the possibility of not having a viable pregnancy, she was surprised to learn that her baby was growing. She made it to 27 weeks before being faced with her next medical challenge to her daughter.

I was twenty-seven and three when I had her, and as that day went on, I felt fine. We did our stress test. stress tests three times a day, and you know, it got to be done with dinner time, and I couldn't eat. I just felt so off and I felt really similar to when I initially went in with her. My body did. Just really tight and really uncomfortable. Um, And, then so we started our stress test, and I, um . . . Well, I went to the bathroom and saw that there was blood, and that I just felt weird, and so I called the nurse in. We got on [monitors], to see how [[Josie]] was doing, and her heart rate was all over the place…. And, so, you know the whole time I am just sobbing, and trying to prepare myself for (crying) all the things. I’m just continuing to say the Lord’s Prayer over and over again at this time (long pause. Crying). And it was, it was just funny because, like [Dr. x] and the rest are just having casual conversation, and my husband’s there like holding my hands. But I’m just so focused on (long pause) just hoping that she is going to make it (sobbing) you know? So,
I’m continuing to say the Lord’s Prayer over and over again, and um, and then they take her out, and you know, NICU, team is there, but they work so quick and so quiet, and um and she let out a scream. Like you don't expect that from a twenty-seven-weeker, or you know, their lungs. She let out a like a screech that like just shattered any shred of doubt that I could ever have had for her.

As she described this up and down journey to her daughter’s birth, it is apparent about how the experience of the nonlinear medical progress of her infant could create a deep sense of fear and instability for the mother. Here Brooke offers an articulate description where she placed her focus on the health of her daughter. She remains fixated on what is happening outward, rather than what she is experiencing internally. This magnifies the task of juggling this external factor instead of focusing on her personal emotional experience of the events.

NICU. Several of the participants shared about experiences of their infants’ nonlinear medical progress and the emotional rollercoaster ride associated with this process. Many of the participants offered stories that were about their infants’ medical progression followed by stories of regression. The women described medical challenges their infants suffered which were frightening and disheartening. Ellie stated clearly, “It's such a roller coaster. It's like you have a good day, and then you have a setback.” Later in her interview she again referenced the emotional ups and downs that she had to endure while watching her infant struggle. She shared, “And I think that was even you know one of the things that I had like cried about to [Dr. x.] I was like, ‘and I know that I said it was going to be a roller coaster. But it's really a rollercoaster.” Ellie recounted some of the process her son went through on his medical journey. She identified feeling connected to his failed attempts to get off medications, and the sense of hopelessness that followed.

He really struggled with like hypoglycemia. And so, it just felt like every time they tried to wean him off the dextrose, you know, in his IV, he would have another low sugar, and so we would like fail that wean…Yeah, it just was like one step forward, two steps back. And then there was talk eventually that if you couldn't get off this IV sugar that we might
have to try this medication, and it comes with a side effect potentially of like heart failure. And so that was just this looming thing. It was like every low sugar I was like, okay, we're just closer and closer to like having to try, you know.

Brooke also discussed her experience of watching her daughter suffer multiple illnesses and recoveries. This nonlinear progression caused Brooke a significant amount of vacillation between hope and despair for her infant.

She was diagnosed with NEC [Necrotizing Enterocolitis] when she was like thirty-one weeks gestational age. And so that was like our first real scary thing that we were unsure of. And she was great. She ended up responding really quickly. She was, responded, really, really quickly to antibiotics. So we are really thankful for that, and it was almost like instantaneous that it was she got on antibiotics, and then we did another x-ray a few hours later and all of the swelling had gone down and the fluid was gone. And so we are very, very blessed there. It was, I mean, obviously it was devastating. That wasn't the one that was scariest, I mean it was super, super, scary.

Brooke shared more about her daughter’s responsiveness to antibiotics and quick healing. She shared about a brief period of wellness followed by another medical complication her daughter contracted which created great distress and uncertainty.

Then she was cleared up, and we got her picline out, and she was doing great for a couple of weeks, and still doing great on CPAP. We were on very low flow for most of our time. It was in March, towards the end of March, so really like two weeks later. So, I guess she was probably diagnosed with NEC by thirty weeks gestation. And then I want to say it was around thirty-four weeks, that I came in, and they had her, we were able to get CPAP off, and I came in, and they had CPAP back on. And I was like ‘what's going on?’ They were like: “Oh, her, you know, blood oxygen, it's just a little low”. I was like, ‘Well, that's really weird,’ and so I went to do her care time, and her labia was swollen. Like crazy swollen! And she was in so much pain when we tried to change her, and it happened so fast.

Brooke described a dire and dramatic diagnosis of sepsis. She shared the story of learning of her daughter’s illness.

That night I stayed late. and um, we got a call from [Dr] in that night that her blood culture showed pretty quickly that she had sepsis and yeah (crying), and so they had to do a spinal tap to see if it was in her spinal cord and um (long pause). And so it was like one of those calls, you know, [Dr.] called me at like ten o’clock to tell us that it came back positive for sepsis, and I just remember looking at my husband and saying, ‘we’re fucked. She’s gonna die if this is meningitis’ you know (pause).
As quickly as things had turned negative, her daughter fortunately responded rapidly in a positive direction. Brooke stated, “we got there, and her gram stain showed that it was not in her spinal cord, thank God! And she had been responding again so quickly to antibiotics.”

Ellie reiterated the back and forth and difficulty she faced due to the unpredictability and uncertainty of her infant’s medical progression. She said,

just the constant like whiplash of it all was like very, very hard…just yeah, the ups and downs were hard, you know. It's like one day where it was, he gained a lot, and we were so excited. And then the next day I was like, Oh, he's actually in fluid overload, and you know, like that wasn't actually a good gain.

Abby also described ambiguity about her daughter’s health and a lack of clarity about what to expect medically for her daughter. She expressed deep frustration and worry due to not having the information she had requested. She stated, “They kept saying, ‘We don't know.’ I kept getting, ‘we don't know yet, we don't know yet. She could outgrow it. We're not sure. We need to do more testing. We need to do more echoes, we need to…’, you know. So, it was so frustrating…” This lack of clarity left Abby uncertain and fearful about how her daughter’s health would progress.

Trauma of infant’s struggle. Several participants shared about the intense trauma they had to witness due to being present for life-threatening moments with their infants. Several women shared feeling deeply afraid and often responding with an acute stress response. Brooke discussed the trauma of watching her infant being resuscitated after just having a successful surgery.

The surgery day came, and I got there, and she was great, and it didn't take as long as I was expecting. It was really only a couple of hours that she was in surgery, and then they started wheeling her back from surgery. And she's just a tricky little gal. She likes to make us think that she's good when she's not, and so they extubated her in the OR and she was doing great all the way over until we got to the room, and then I looked over, and I was sitting at the couch next to the window, you know, and I looked over, and she
looked different. All the doctors had left at this point, and she just like looked different. She looked gray, and she wasn’t breathing…and (silent crying, pause) and so, you know, thank God for our NICU nurse, and our respiratory therapist [RT] was right there, and so, uh (crying) they were there and jumped in really quickly. But of course, in that time you feel like It’s like thirty minutes until people are doing stuff. And so I’m just like freaking out. Telling everybody to just ‘save my kid, hurry up, do your job. Save my kid.’

She described her experience of having a trauma response and the fear that was associated with trauma of watching her child nearly die.

It just, it was obviously super scary. I wanted to fight, flight, freeze all at the same time. And (crying)um, you know, when they got her breathing again and put her on CPAP. Um…. But…. she ended up being fine. It just it was obviously super scary… and now we're like at the end of the tunnel, right? We know that once we get the G-tube placed we only need a week to make sure that it works, and then we get discharged. Yeah. And now she's back on CPAP. I just watched her stop breathing for a long enough time that I was like ‘Is she gonna have brain damage from this?’ You know, it was (pause) It's hard in the NICU because, especially as a mom, it's hard not to feel like resentful. Because my husband's wonderful, and he does such a good job, and he works so hard. But he's a, you know, he has his own business, and so he didn't have the leave that I had…and so it's hard not to like, uh grow resentful over that [being the one seeing the trauma].

Andrea noted her own experience of watching her son’s oxygen saturation drop to the point of alarm.

I was there for probably 45 minutes and then his oxygen level dropped and they were you know, they give them that leeway of a few seconds to let them try and recover themselves, and he wasn’t recovering. And then (pause) I mean, the nur- . . . like it’s not a panic, but it’s like a “okay we need to do this” (snapping her fingers). They get on it, and you are just standing there and you’re in the way but you don’t want to move and so you are just freaking out…And frozen. I sat down on the chair and I just sat there and I, I, was, I just started bawling because you know, you can’t do anything. Yea and you’re just watching, and you’re just hoping that whatever they are doing is going to work.

She continued to share about the seriousness of the trauma she had just witnessed and the impact that the event had on her.

And it did (intervention worked). Luckily. And then they put him on a little bit of oxygen for I think 24 hours after that, just to kinda catch him back up, and make sure everything was okay. He just had a little, a dip, and that was pretty traumatizing, and I kinda forgot that had happened (laughing), but then that whole thing happened, and I was like, I need to like leave for a few minutes and just kind of like go back to my room sit
there and maybe just lay in bed and feel sorry for myself and cry (laughing) and just, you know, just be. Once I realized he was okay and everything.

**The Deep Dark Battle**

This theme is defined by the emotional internal spiral that lived at the core of women’s experiences in the NICU. All of the participants identified feeling aspects of isolation and being in internal turmoil with their own feelings of failure, helplessness, and guilt. The spiral inward is comprised of subcategories of loneliness and isolation, trauma, “good mom/bad mom” dichotomy wrought with internal messaging, guilt, and in the deepest recesses, a sense of personal failure, uselessness and despair.

Ellie summed up the different aspects of the deep dark battle: the isolation, the pressure upon the woman, and the sense of responsibility she must hold when outcomes are unpredictable.

The self-judgment and like, critic . . . , I just I wish I could go back and like, be kinder to me. . . . I, I, think I’m still on the journey of forgiving myself (begins crying), forgiving myself for, I think just the responsibility of . . . , that’s the thing about being a woman is . . It's all on you, you know? Like to get them here, to get them here safely, and when that doesn't go to plan it, just the guilt is like...you know?

She captured many aspects in the downward spiral in this statement: “And then once he was moved up to special care, and I could room in with him that obviously was amazing. You know I could hold him all the time.” She expressed her deep satisfaction in being able to be with her son and have consistent proximity to him. She continued on:

So, and it just, I think, when I was rooming in, it was a little bit isolating during the day you know, my counselor would be like 'It's a good idea to go outside and like, take the walk,’ and... easier said than done...But yeah, I guess, new mom role, really figuring out how to, how to balance when I need to pump and holding him, you know, like, I think, that's one of the hard things about like being a first-time mom in the NICU, during a pandemic you, it just was so isolating (begins crying again).

Here, she highlights her experience of isolation leading to loneliness and internal messaging about being a “good mom” (not leaving her infant, holding him at all times) followed by a sense
of guilt. Her guilt presents as being torn; having to make a decision to either hold her infant or pump in order to feed him. And later, choosing between a constant presence with her baby and leaving the hospital room. Ellie’s statement highlights the first layers of the “deep dark battle.”

The “Deep Dark Battle” reveals experiences of internal suffering. As participants shared, different stages of the deep dark battle emerged. First women discussed feeling very isolated and lonely. All of the participants shared about their experience with isolation and loneliness. Abby shared, “Oh, it was extremely lonely. That part [being on her own]. Yes, that was extremely, extremely, lonely and isolating and I had a hard time even asking for help. I would feel guilty asking my mom to do stuff. And, there was no one to talk to. No one. But it was so hard, and it was so isolating, so isolated.”

Participants also discussed rigid internal messaging of their mother role that amplified their suffering. Although not described in these terms the women all revealed a sense of “good mom/bad mom” dichotomous thinking. In this subcategory women explained over and over, how they attempted make decisions and contributions that were about “being a good mom.” One such message was that “good moms” make their babies the only priority. For example, Ellie shared, “like, it was just me or [Tom] (son), and I was always going to choose [Tom].” Likewise, Jessie described internal messages, “a good mom puts her child first and makes them the priority.”

Beneath the internal messages and thoughts about being a “good mom/bad mom” lives the deepest part of the battle. In the lowest, grittiest part of women’s experiences in the NICU, participants described a deep sense of suffering due to a sense of failure, uselessness, hopelessness, guilt, and desperation. Lindsay described her experience of feeling helpless and useless while being unable to help her son during his stay in the NICU. She shared,
I felt really, kind of, you know, helpless or useless, or, I mean (pause) to just be in a situation where we can't really like exercise, a lot of control. There's not much to do to like direct the outcome. It's hard. So that was that was the big challenge. I just felt like that was just really hard. Um, And. you know just that feeling of like that's not the way that it's supposed to be.

Abby offered a concise statement that addresses her experience, “It was the worst month of my life.”

Subcategories of the Deep Dark Battle surfaced as: **Lonely**, an experience of being isolated, and emotionally on their own. Another subcategory of this theme is **Good Mom/Bad Mom** **Dichotomy**, in which women shared internal messages they told themselves and felt pressured to live up to. Subcategories of **Guilt, Failure, Shame** and eventually **Personal Despair and Hopelessness** also emerged from the theme of the **Deep Dark Battle**.

**Lonely**

All of the participants of this study described loneliness during their infant’s stay in the NICU. Though participants did express experiences where they were physically alone, that challenge was something that they all seemed to be able to manage. However, participants articulated a lonely isolation in their own emotional suffering that was incredibly difficult.

Andrea articulated her experience of loneliness as a sense of loneliness in the midst of others. She stated “Alone, in the midst of other people and everything is happening around you still, and you are just kind of there-ISH. Physically there, and mentally, probably not.”

**Isolated**

Several participants described isolation as their experience in the NICU. This isolation occupies an internal, singular experience which no one else could enter or share. The women described simply existing with no meaningful connection. Andrea described being surrounded by people and still finding it difficult to get out of what she described as a daze. She shared,
Not that I didn't feel supported in the NICU, I just don't think I was able to really build any connections in the NICU…And I mean, it's not like you can really talk to those parents anyways because they're, you know, they're behind the curtain. And then . . . they're stressed out and so you can't really have conversations with them anyways, you're just, . . . all kind of in a daze, and you're just like sitting there eating your granola bar and eating alone, eating your banana alone. And, I'm like, ‘Why am I not talking to this person? Why am I not reaching out?’

Ellie shared about her isolation and internal loneliness while trying to breastfeed. She reported

“And just doing all of that (breastfeeding) alone was so isolating. This is very, very isolating (crying).” Brooke also referenced several times throughout her interview, “Yeah, we're super alone. We're super isolated…it's like, yeah, yeah, very isolating.”

_Emotionally Alone_

Participants also discussed their sense of being emotionally alone. They described the feelings of being in a situation that can’t be understood by others outside of the experience, and a deep sorrow for the lack of emotional support. Abby discussed messages she received which drove her to remain “strong” and hidden in her struggle:

But at the same time she's (participant’s Mom) not a very, like, emotional person . . . like how I am. And so, whenever I would be crying or upset, and stuff, she would kind of just like, brush it off and say ‘you need to be grateful that they’re (infants) okay or they're fine.’ And you, you know ‘they're gonna be home soon. Just don't get upset,’ And it's like, ‘don't tell me that, I need to feel the way I’m feeling.’ It was super hard because I didn't have anybody like validating my feelings. Like no one. And I had to just pretend like I was okay…I still struggle with that, and I still kind of have a little bit of resentment around that because it was more of like, ‘Oh, you're being weak or showing a sign of weakness.’ Or you know, ‘Don't be emotional in front of the boys because it's going to just upset them.’

Later in the interview Abby reiterated her loneliness and isolation with her feelings. She noted,

“It was like I said it was hard, because there, there were times where, like I couldn’t show weakness, you know, like I couldn’t cry if I wanted to. I couldn’t lose my shit if I wanted to. I
couldn’t. I couldn’t have a meltdown. I couldn’t just say like this is not fair?” Andrea discussed feeling challenged by being emotionally alone and an existential experience of being alone.

I definitely think emotionally I felt very isolated. Yeah, my husband, I don't think could, (pause), I think anyone who's a mom who's had a baby, I don't think...I mean, husbands sort of get it, but I don't think they really can understand how a mom feels. She continued, reiterating how alone she felt, describing a moment when she began to express her loneliness through tears and was met with further disconnection and misunderstanding:

And, um, and my husband's like, ‘You don't cry. I don't know how to even comfort you.’ Because I'm not a crier, and so he's, he, I think just didn't know even how to comfort me. And it was, I feel like it was really isolating because I didn't know anyone who had gone through the same thing as me, at that time.

Similarly, Ellie articulated her internal struggle with being alone as she navigated her first time being a mother to a medically fragile infant. She shared, “That's just, that was hard just learning to be a mom for the first time, just pretty much on your own. That was really, really hard...really isolating.”

**The Pervasiveness of Death**

One subcategory that emerged from the data within the Deep Dark Battle is about the fear that women withstood as they walked the halls of the NICU. Women expressed a chronic knowing that their infant, though alive and possibly doing well at the time, could take a turn for the worse. The women described an awareness and internal suffering connected to the realities that there were babies in the rooms around them medically worse off and even dying. The acute awareness of death and injustice created an ongoing fear, hypervigilance, and sometimes gratitude that participants navigated daily. Lindsay explained:

I think it's pretty common for, maybe women, to say to yourself, ‘But it could really be so much worse,’ you know? It could really be so much worse. And you look at...the monitors, and you can see all these other babies names, and you know that, there are babies that um...um, I definitely should be feeling so lucky. And I do! You know, I do.
But it doesn't mean that your experience is not also like challenging for you, you know? So I just remember that that was something that I really felt like acutely while we were in there.

Andrea discussed this experience when she shared about walking through the halls of the NICU and being saturated in the awareness of the possibility of death around her.

I think the added anxiety too was, you know (slowing down), hearing all the alarms going off and you know, they have your baby's primary screen, but you can see every other child. And when like a stat drops, or, and you see like, and you hear the alarm and...like what's going on, to somebody? And in just hearing those alarms, too, just makes you like, ‘Are the parents there when this is happening? Or in, you know?’, It’s so many thoughts like run through your head.

She continued sharing her understanding that other parents were experiencing the worst-case scenario of their babies dying. Here’s more about her emotional experience of this knowing:

Or like there, we know it's one baby that happened, and walking by some of the rooms, you're just... heart just breaks into a million pieces for parents, too. I think because you know how they feel but you also don't.... yea. Like, ‘That doesn't look good. This is not looking good.’ And I mean, there was a few babies that happened to [died] while [Sam] was in there. And so, I think that that was like, a pretty traumatizing thing.

Brooke described being closely connected to one baby who died. While she was preparing for discharge, she simultaneously engaged in supporting her grieving friend. She wept as she shared, “And so um (crying), and so, it was that week that we were getting ready to be, actually it was the night that I was staying overnight at NICU, so I can learn the pump at nighttime. And that night we actually had a memorial service for [Sloan].” Later in the interview, she revealed her own sense of hopelessness, when her infant battled multiple threats to her life. When asked about having dark days, she responded,

Interviewer: you had days that were pretty dark in the NICU?

Brooke: One million percent, one million percent (describing her own experiences of emotional darkness). Especially when she (daughter) had sepsis. It’s like I felt like I was gonna die from heartbreak, you know, like the thought of...And I remember saying several times to [Cash] (husband) that like, ‘If something happens, if something happens
to her, I don’t know what's gonna happen to me. Because I just really truly feel like I would, I would die of a broken heart if something were to happen to her.’

Ellie described her hypervigilance and inability to experience happiness or peace in the midst of her NICU journey due to the chronic fear of illness or death striking her son. She relayed the intensity of her fears and the thoughts consumed her mind:

I almost felt like…I don't know. I remember, like some of the nurses saying like, “He's doing great. He's doing fine,” almost like I was like being too hard on him. And I think it was just . . . my own anxiety . . . ‘How is this all going to go?’ You know? So everything was like such a big deal, and I think just because they're (the nurses) so used to ’t that they're like, ‘Listen, look! Your 33-weeker is, not even on CPAP. Be happy.’ And I’m like, ‘But I can’t, because I’m so worried about x, y, and z, you know? …And [my worries about what could go wrong] were just all I thought about. I finally did have one day that sticks out in particular, where I just like, broke down and cried. I’m usually not a crier, or…in the moment, of course, later, talking about it is one thing. But yeah, that was just a day that felt like, very, very low. Yeah, it was hard. It was just… It was all I thought about.

Lindsay named the gratitude and reality she felt knowing that they somehow escaped much more sorrowful outcomes than having to stay in the NICU while also holding how difficult her experience was. She expressed,

I did feel like very, very lucky, because I felt like, all in all (pause) . . Um, it was the best we could really hope for. For you know the situation, and my situation. And um, yeah, so definitely, this feeling of like feeling lucky, but also being like this is one of the hardest things I have ever done, you know.

Participants described their experience with the pervasiveness of death as they navigated the NICU with their infant. They discussed experiencing distress knowing that their infant could potentially die, and more prominently that there were infants around them who were dying. They described an element of increased anxiety and hypervigilance and at times gratitude that their journey wasn’t that of some of the other moms around them.

Good Mom/Bad Mom dichotomy
The “Good Mom/ Bad Mom dichotomy” identifies intense messaging internalized from societal norms and participant’s own thinking. As the women shared their experiences, it became evident that they were desperately yearning to be a “good mom” while simultaneously actively pressuring themselves to avoid doing things that “bad moms” would do. In this subcategory, women identified a rigidity in their narrative about what defines a “good mom”. They described having thoughts which were often “either/or” and “all-or-nothing” based. For example, women discussed internal messages about “right and wrong” ways of feeding and ways to offer care to their infants. They expressed rigidity in thinking of what they could offer their infants to qualify as a “good mom”. This emerged in “either/or” thinking such as: decisions to put the infant first over themselves, and thoughts of needing to contributing in a specific way or thinking they couldn’t contribute at all. Participants also shared their thoughts about how much time, energy and effort “good moms” give to their infants. Ellie noted that she was critical and unkind to herself throughout her NICU experience and did not allow herself the grace to stray from internal messages, “It’s interesting. I tell my counselor all the time, like just the compassion that I would have, for, like other people going through this (crying), I just was never able to give to myself.”

**Good Moms Pump and Produce Milk**

The good mom/bad mom dichotomy appeared in messages about pressure to breastfeed and pump, and the value that breast milk contributions held about the women’s status as a mom. All of the participants spoke about their breastfeeding and pumping journeys as a way to contribute and care for their infants. Here Jessie said: “I was, I mean, I’m still breastfeeding, but I was trying to breastfeed because he didn’t . . . . and so, I was pumping, providing milk to him um, trying to get him to latch um, and so I was like, that’s one of the main reasons why I was so
consistent. Because I was like trying my best to ensure that he was gonna get, to be able to eat.”

Brooke reiterates the pressure regarding providing breastmilk. She shared,

I just wanted that so badly with [Josie], and you know there's a crazy amount of pressure on moms, and I think that there’s pressure of providing nutrition for your kid, like your own nutrition, for your kid is heightened tenfold when you're in NICU. Because you know, you know, obviously, “fed is best.” But you also know that like they need those antibodies. And so, you feel like a crazy amount of pressure.

Many hospitals have adopted a narrative surrounding “fed is best,” highlighting that breastfeeding, breastmilk, and formula all provide nutrition to the infant. In fact, in many cases, NICU’s must supplement breastmilk with high calorie nutrition. It is important to notice that the pressure Brooke references is not a pressure that is spoken or implied from medical staff, but rather a message internalized as a way to contribute or “be a good mom.”

Ellie discussed her immediate desire to begin pumping, because of her knowledge, and internal messages she held of the value of producing milk. She shared about the internal pressure she felt to begin pumping, in order to hit her standard of “a good mom.” She shared, “And then my immediate thought was like, I just, I wanted to start pumping, because I remember the lactation consultants talking about how important it is to get that stimulation as soon as you can.. I just kept asking and like, ‘Okay, can I pump now?’”

Lindsay expressed a sense of value coming from her ability to produce. She shared,

Yeah, I really like channeled that [desire to contribute] into pumping, you know? Because, I was concerned that my milk supply wouldn't come in, and that was really, really important to me. I put a lot of value on that, .... I had like a lot of milk, and I remember feeling like really good, because I would like bring it to, I would bring it to the NICU and I felt like it was like like literally- I felt like it was the ONLY thing that I could provide for him in a way.

She also noted that she was invested in pumping and in her son’s time in the NICU she didn’t miss any of her pumping sessions. She explained, “So I just remember feeling like, here it is, you
know, like this thing that I can. I have a lot of it. So that was really good. I did not miss
(pumping)."

**Good Moms Spend all of Their Time Present**

The *Good mom/Bad mom dichotomy* also presented in participant’s commitment to be present in the NICU throughout the majority of the day. Participants reported feeling as though they needed to be present at all care times. Abby articulated this by saying, “I kept saying like, am I here enough? I, I feel bad when I have to leave,…because I felt so guilty (begins crying again…pause).” Ellie echoed this concept of messaging as she shared, “the thought of like missing a care time like I just I wanted to be over there all the time.” She continued on, “I still felt that guilt of like that I have to be up for, like every care time, you know? Because I felt like I was going to be judged like I wasn’t a good mom if I was not present, and participating in every single care time. So, then I just wasn't sleeping, and I think that was, you know, a huge part of it.”

**Good Moms are Selfless**

Participants also described messages that “good moms choose their babies’ needs over their own.” Abby explained how her self-messages about being a good mom informed her decision about having a C-section. She explained about being a survivor of sexual abuse and the vulnerable place that having a C-section would put her in. She explained the decision she had to make between choosing a delivery that would meet her own desires and needs or doing what was likely safest and best for her infants. She identified that putting all of her own needs aside captured the definition of mom. She stated:

> Because it's [natural birth] something that I really wanted, and because I don't want to have to undergo surgery, I don't want to have to put 'y body through that, I don't want to have to, like mentally go through that, you know, and emotionally and physically. Or do I just put all of my needs aside and do what's in the best interest for my babies? And of
course, that's like to me the definition of being a mom…So it's like, you know, I had to choose my battle. I had to choose what was more important to me, and of course my babies are more important. Their health or safety is more important.

This statement is eye-opening when examining Abby’s thinking about the ways a “good mom” behaves. These insights reveal how the women in this study dialogued with themselves. Ellie highlighted the messaging she internalized that “good moms” put their baby first and all their attention is on their infant. She noted that after her son’s admittance to the NICU, she put even her most basic needs aside.

It's like I needed someone to take care of me because I wasn't doing it. Like, you know, just even like the eating and drinking thing, and going to the bathroom. And you know, like, it just was such a night and day difference from when you're pregnant, and they're still in your stomach, and you, you're used to taking care of yourself and then, all of a sudden, it was like, I just, I just didn't... I just was focused on him twenty-four seven...

Andrea reiterated this messaging by sharing her own internalized stories when talking about sacrificing her own physical pain to get to her baby

Obviously, I feel like it just is a testimony to women, and just being like, ‘I don’t care, I want to go see my baby no matter what.’ And thinking about it now I’m like well that was kinda stupid (laughing) but, I mean, worth it. Obviously. But yea, you just don’t even, you don’t put yourself first anymore.

Similar to the message of “good moms put their children’s needs above their own” many of the participants operated with an internal message that good moms don’t take time for themselves. Brooke and Lindsay gave clear examples of the beliefs they held themselves to.

When telling a story about being encouraged to seek outside mental health support Lindsay shared her internal thoughts which helped determine the decision to not take time for mental health support for herself. She identified having messages from around her that good moms don’t take time to care for themselves. She said, “You know, what kind of mother does that? We're given all those messages.” Brooke shared her experience of feeling guilt after being encouraged to take time for herself and seeing the contradiction between her feminist identity and
internalized expectations of being a ‘good mom’. She said, “Like the feminist in me, it's like ‘Well, this is bullshit.’ You know? Like, why is this the way it is? But then, even so, I’m like, ‘But if I take time away from them, what kind of mom, am I?’ You know?”

**Good Moms Don’t Ask for Help**

This dichotomy continues to represent a deep level of self-judgment and criticism for the women. Namely that “Good moms don’t ask for help.” As women shared about their internal resistance to ask for, or accept help, it strengthened the concept that women felt there was a “right way” and a “wrong way” to be a good mom. Lindsay shared, “But yeah, I didn't. I didn't end up, you know, taking any, a lot of the help that was offered to me. (laughter) I don't know why, just, I couldn't.” Lindsay described a moment when she felt that by accepting help she would be engaging in “bad mom” behavior. She shared,

Well, you know, I was definitely offered a lot of um, like counseling support. Which was good, although I didn't necessarily want to take it, and I don't know why. Well, I do know that partly I felt like ‘who has time for that?’ I don’t have time for that right now. That that would be indulgent in a way (laughter) it was my thinking at the time.

Ellie discussed the intense pressure and judgement she placed on herself about not asking for help, “And also I think because there was the added stress of like (voice quivering), because I worked there (NICU). I felt like you should know all this. You work with babies, you know babies. Like you have to get this right away. You can’t ask for help. You can’t.” She also noted the consequences of this thinking, “But (pause) you know that was an added barrier to feeling like, you know, supported (tearful).”

**Other Moms**

This dichotomous thinking was presented in judgements and expectations about other moms in the NICU. The women described their own judgement and narratives around bad moms. Abby stated, “I would be like a lot of those other moms, and have to just come once or
twice a week ’r a couple hours a day, and that's it.” Brooke was more blatant about her
judgements and reported an awareness of them. She described a changing perspective since
being in the NICU. She expressed,

> There are all ends of the spectrum in NICU. You have babies who are, unfortunately, coming off of drugs. You have babies who have like a pretty typical home. And yeah, it's just, its, an odd place to be, you know…it really helped me to like tame some of the judgment that I tend to have. Like towards moms and parents. And like, because yeah, NICU doesn't discriminate right?

As women shared about their messaging towards themselves, it also became clear that they were making attempts to “self-correct” their downward spiral and prevent further emotional distress by meeting high standards and judgments of “good moms.” Ellie offered an example of messaging with intentions to help. She shared a story about her experience in which she attempted to do something to support herself to move out of what she identified as a “spiral down.” She left for a meal out and was unable to get back into the hospital due to unforeseen lockdown initiated by the hospital. She described the messages she gave herself about the kind of mom she was because of this decision. She shared, “And that was just another moment of like, Okay. See? You took a couple hours for yourself, and like, ‘see what happens?’

Like…which isn't even true. But you know, that's what it felt like at the moment. Like just a reminder that this is why you can't let your foot off the gas. You have to beat yourself, up every hour, of every day.”

Alternatively, Jessie had a different experience. She identified that a part of her ability to experience a sense of calm was due to her infant doing well. She identified how and when she would begin questioning her maternal abilities had her son’s health been worse. This questioning fits within the good mom/bad mom dichotomy as it highlights the internal messages that good moms fix it and good moms are responsible for their infants’ wellbeing. Jessie stated:
But I think the one thing that made me calm was his calm. Yeah, and I think that's the main thing like, because if he was in distress, if he was like not able to breathe, if he was not able to eat, I think I would have been, this, you know, in that fix-it mom mode like What can I do? What am I not doing? What am I doing wrong? But at that time I was doing everything I could, and he was doing well.

Participants articulated strong dichotomous thinking and messages they held about what makes a good mom. They identified messages they held that supported this thinking and negatively influenced their downward spiral as they worked to achieve good mom status. These messages included: Good moms pump and produce milk, good moms spend all of their time present, good moms are selfless and good moms don’t ask for help. This internal rigidity in messaging added distress and negativity to women’s experience of having an infant in the NICU.

**Guilt**

All of the participants in this study talked about their intense emotional experiences of guilt. All the women identified internal guilt that was related to having to make forced impossible choices. The participants of the study were faced with decisions about where to put their time and energy, when to stay or leave the NICU, and even perceived medical choices when decisions about care held no reasonable alternatives. Several of the participants had children at home and often needed to decide which child they would focus on. At times, decisions were made for the women by medical professionals, such as admission to the hospital and discharge, and leaving their infant at the NICU. Even in these forced decisions, women experienced internal guilt and distress. Ellie revealed her emotional experience after delivery was a combination relief and long-lasting guilt. She decided to have a C-section to avoid risk of harm to her infant by remaining pregnant: “And unfortunately, the relief, gosh! Only lasted such a short period of time, and it's like I feel like I still struggle with that (guilt). That, that guilt part that has been infinitely harder and longer.”
Later in her interview Ellie discussed the difficulty she faced choosing to hold her infant or pump. She discussed how both decisions had potential consequences for her infant that created internal guilt. She shared, “But that’s where I really, I kind of started to spiral. I think. And then I wasn't pumping as frequently because I just wanted to like, I just wanted to have him on my chest all the time, and it's hard to pump and have him on your chest at the same time, and I couldn't put him down for a second.”

Brooke experienced guilt even before her daughter was born. She was placed in the hospital for two weeks before delivery and was unable to see her son. She shared the distress she experienced:

Yeah, it was, you know, height of COVID, and so I couldn't see my son I, and that was the thing that I was dreading the most right? It was like knowing that I wouldn't be able to see him, because he's so used to Mom [me] doing everything and running him around and doing all the, all the things. And so, um, that was the hardest part of the antepartum, for sure, like I could handle like being by myself and looking at those walls all the time, but not getting to see him was the worst.

Similarly, Lindsay discussed immense guilt not being present and available to her older son. “I felt like I was like shuttling [Sage] around to different places for people to watch him, like piecemealing kind of like childcare for him, while we would go to the hospital and stuff because I felt like it was just this huge shift for him, and I wasn't there to like support him, and he might feel like kind of abandoned in a way.” Abby also had children at home while her daughters were in the NICU. She too articulated the sense of being torn between two impossible decisions of where to be. She reported, “but I just felt so, so guilty when it was time to leave [NICU], and I would cry every single time (crying again)... and then, I cried a lot. When, because, I felt like I wasn't being attentive to my boys’ [at home] needs as well.” Abby again stressed suffering due to her inability to be “present enough” in any area of her life. She said, “the guilt of, ‘I'm not spending enough time with all of my kids.’ The guilt of, you know’ like I
can't take them home. I can't be there for my older kids. I can’t be involved. How I need to be as a mom.” Lindsay discussed the tension she experienced knowing that she needed to be two places at once, and her difficulty staying present where she was, ultimately adding to her guilt.

She stated,

Where I think about like . . . . when I would be at the NICU, I would be like thinking about [Sage], or feeling like I needed to be at home, and then, when I would be at home, I would be like rushing through things and thinking like, ‘Okay. Well, we just have to get back to the hospital,’ you know. ‘We just have to get back to [Seamus].’ It’s really terrible how you, how you do this to yourself, because then you end up like being not present for anyone.

Abby shared a similar story of being torn and experiencing guilt. She communicated,

“and that was the first night I did not spend the night with the twins, so I spent the night at home, so I could wake up with the boys for Christmas. Then, I’m over there just crying while they're opening gifts and stuff. And then, like, probably, after they open their gifts, we had breakfast together, I'm like, okay, I'm gonna leave now and go be with the babies.”

Several participants also discussed how their need to ask for help elicited feelings of guilt. Abby shared, “I would feel guilty even asking my mom to do stuff.” Lindsay acknowledged her guilt when asking for support from others. She shared, “You know, feeling really bad in a way to ask for so much from everyone.” She continued on, “although I know that if it were reverse I would never want someone... I would always be like ‘Oh, of course!’ you know, the same as they were, but you still feel bad having to like, just receive from so many people.” Brooke described being torn between even her work and her daughter in the NICU.

And also, still feeling guilt over not being at work, because I would be getting emails from my students. I teach middle school, you know. So, I’d be getting emails for my students telling me about the horrible time they're having with the sub and how they don't understand math now...And all of this stuff, and you know, so I’d feel so guilty about that. Like not being at work…it's really hard to overcome that guilt too…

She shared some of the social messaging she believes informed her guilt around this.
I think that we just have crazy expectations of moms in our society, right? Like we're expected to do all the things. There's a, like a meme or something, I saw that's like: “Moms are expected to mom, like they don't have a job and then have a job like they don't have kids.” Right? (long pause) . . .

In a different way, Ellie discussed her own awareness of internal messages which informed the critic she was to herself. Ellie shared her experience of identifying an internal message that existed for her by naming and contradicting that same message with a recent patient of hers. She described,

I just told a mom the other day, like her son, was still on CPAP, and you know I just kind of shared my story very brief. Just saying like, ‘You know I personally, I didn't feel like I bonded with my son until like that was gone, and I could really like, see him as a whole. So if you feel like that like that's not . . . You’re not a bad mom or anything like that. That's very normal.

Abby gave a thorough description of her experience of guilt that pervaded throughout her entire experience in the NICU. She described her journey of guilt from birth, through the duration of the NICU stay of her infants, and even into her post-discharge experience. She shared about being unable to hold one of her twins and concerns about bonding. “I didn't want to feel like I was bonding with one and not the other, and that's what I felt… and it was really hard.” She then shared about one infant being discharged before the other and having more one on one time at home with her. She shared her guilt again, “One got to come home before the other one, which… the guilt and the feeling like, ‘How am I gonna leave one baby and not bring home the other (begins to tear up, voice shaking)?’” Finally, even after discharge she reported her continued guilt about this experience, “yeah, and so I always wonder. And that’s in the back of my mind, ‘Is it because I didn't have those moments with her? And because I brought [Marly] home first, and I was able to bond with her more at home before I brought [Sophia] home?’ So that's kind of hard.”

Failure
This part of women’s internal battle is defined by their internal struggle with feeling like a failure. The women described at times feeling responsible for the outcomes of their infants suffering. At this level of darkness, women also identified an experience of anger towards their body failing. Simultaneously, while in the midst of wrestling with their sense of failure, women identified their experience of being unable to do anything to make the suffering of their infant better. They discussed their inability to change the outcome of the experience and event in any way. Ellie described a situation in which she was in a deep emotional struggle and when the doctor was able to see and address her need, when she felt understood, she was able to name the experience she was having regarding her sense of failure. She shared,

Dr. [X], was like, ‘what's going on for you?’ I think maybe that was just a day where she you know, she knew... And she didn't, she didn't have NICU babies per se but she did have high blood pressure during her pregnancy, and, you know, like barely got to term, and so I think that was when I first broke down. It was, I just, I feel so guilty. I feel like I failed him (begins sobbing).

I’m the failed vessel

Participants articulated with poignance their sense of their body failing. Lindsay explained, “It was just really hard for me, because I felt like, how do I want to say this? Like, pretty angry at like, my, my, and like sort of cheated, at my body.” She articulated her hopes for this birth to be a corrective experience from a very challenging birth experience she had with her first child. She described the ultimate disappointment and anger she felt when that was not the case:

I had wanted like, I had decided that this was really going to be this like healing and cathartic experience, and you know, of course I wasn't going to be able to have the ideal birth, because I knew that I was going to have a C-section. That I would not be able. But I still had this idea that…and then, then none of it went that way. You know? Like this healing experience that I wanted, and I was just angry that my body totally craps out. Really didn't, you know, do the job. And so, I was, I felt angry about that, but also guilty, you know, like feeling bad, you know, to see [Seamus].
Brooke talked about her sense of failure, informing her decisions about needing further support for her infant. She described her thoughts regarding her pre-term birth as a ‘failed pregnancy’ and the compounded failure she further felt because of her daughter having to get a feeding tube placed. She stated, “Yea, and so, I was really hesitant to do the G-tube, because I felt like such a failure, in an already a failed pregnancy.” Brooke also expressed her perceived failure by questioning, “Like why? Because it was, I had the best pregnancy with my son, like it was so perfect I felt great. We delivered a little bit early, but not like this.” Brooke wept as she shared about the rigid precautions she had taken to protect her growing baby and the disappointment she experienced despite such deliberate actions. She described, “I didn't even take Tylenol, because I was, you know, I was like I don't want anything to harm the baby. And I would move my body away from our microwave when it was on (sobbing). You know it's just all these things.”

Jessie described her own tension with her perceived failure of her body.

I felt like my body had failed me, though, like it was, I was unable to… Because up until that prenatal appointment everything was perfect. And then it was just like, yeah, it [body] just hit the wall, and then it was like every time I blinked, something else was different. And it was, yeah, we were getting a run for our money at that moment.

She identified thinking about her responsibility in her son’s premature delivery and subsequent NICU stay and the ways that she “should have or could have” done something for a better outcome. She shared, “I, I was like I should have done more, I could have done better. I should have done this, I should have done that.”

**Helplessness**

Another way that participants experienced failure was feeling helpless and useless in response to their infants and their health outcomes. Participants described feeling like observers of their sick infants, unable to provide solutions or support. This sense of helplessness created
internal despair in women. Lindsay stated, “you know you feel definitely helpless…which is hard because you're sitting in there. You kind of feel like a lump, you know.”

Participants described the helplessness they felt upon seeing their infants hooked up to machines and receiving frequent medical intervention. Their stories emphasized their lack of ability to do anything to make it different. Lindsay highlighted, “And you know there's this feeling like you are not, you can't even like, do very much to like take care of your child, which is really hard.”

Abby described a sense of helplessness she experienced watching her babies being sick and having to endure procedures and treatments. She shared about both her protective instincts and ultimately being left with the feeling that there was not much she could do to help her babies.

And it's like, and to see them be poked and prodded, and get their blood drawn and get their nasal cannulas in, for you know their oxygen and CPAP machines, and all this stuff. Like instantly, like you, those mama bear claws come out, and you just want to protect your children. And like, you know, you see, nurses there. It's their job. It's what they're trained to do, but they're not always so gentle. And here my little tiny, helpless four-pound baby is over here screaming hysterically and her heart rate's going up. Which it shouldn't be going up, and you know? And I'm over here like, ‘What do I do?’ There were times where I had to say something and say, ‘You need to be gentler, or don't be so rough with my baby,’ or say, ‘Let me just hold her for a second, and calm her down.’ And That was extremely hard for me, extremely, because I have a hard time sometimes standing up for myself and for speaking up. And it's something that I really work on, and I try to. And there were times where, my mom would look at me and be like, ‘say something,’ or be like ‘If you don't say something, I’m going to.’ And so, I had to say something. But I didn't want to come across as like unappreciative, or that, I didn't value them, or think that they knew what they were doing. But I had to…. And there were times where I didn't say something, and I regret it.

Andrea shared about entering the room to see her baby for the first time, and her immediate experience of feeling helpless and overwhelmed. She stated, “you know, seeing your baby on like a life ss (support)… (pause) he was on a CPAP machine, and then he was so tiny that they couldn't get a vein in his like arm and so it was in the little, the top of his little head and
that just sent me over the edge, was very emotional.” Similarly, Lindsay magnified her feelings of seeing her helpless infant be treated. She explained, “And he's just like barely five pounds, and you know, it's sad to see, like with um, you know, the um, IV coming out. They have like, stick it in his head, and it just looks so sad. Yeah, you know this, my like, little baby.” Lindsay later described an event of her infant’s oxygen dropping and his alarm going off and her sense of helplessness. She reported,

you know, totally helpless, or clueless. It’s like, when you like, try hold a baby, hold your baby, and then the alarms are going off and like, just constantly alarming. And then the nurses are coming in. Um, that’s… I dunno, ‘Take them, because I don't know why this is happening’ (using a stressed voice), or . . . and it's freaky. So that's what I was feeling like, useless or like, very helpless.

Abby, too, articulated her feelings of not being able to help with no control of their discharge. She stated, “just feeling helpless and feeling… I felt hopeless, too, like I felt like this was never ending, and I felt like we were never going to get to leave.”

Shame

As participants spoke about their NICU experiences, the theme of shame emerged. Shame is described by the women as the deepest kind of failure; a sense of ownership and self-blame. Shame is about the ways women in this study internalized their perceived failure and carried the emotional burden of that perception.

Abby described her avid and often unsuccessful attempts to help her infants get well enough to leave the hospital. Her self-narrative held beliefs as though something were wrong with her. She expressed,

And I would try and try so hard to like get them to breastfeed and get them to latch on, and get them to fall asleep, And I thought like, oh, it's because I’m not doing something right, and I’m not getting them to be able to eat, and you know. So, I had all, this feeling like… like, what am I doing wrong that is, preventing them from being able to come home?
Abby also shared about her experiences with deep guilt and questions about being responsible for the outcome of her infants, “And the other part was just feeling guilty, like, okay, did I do, do too much during my pregnancy to make myself go into early labor? Like I could have prevented this.” Ellie described a very personal and internal felt sense of responsibility watching her infant suffer multiple medical procedures:

I think because the relief for me right after he was born was like was so high, you know, like. And then you . . . It was a few days later when, like his blood sugar started tanking. That was when, you know, he ended up eventually having to get like an umbilical line. Because he had to be on like higher amounts of Dextrose through the IV, and that's when I started to like second-guess myself like and blame myself (voice shaking). You know, like, like you shouldn't have chosen the C-section you should have like gone with different interventions. You know what I mean’ Like, so it was like it was this high of feeling like, Okay, he's out. He's safe. And then when I saw him, you know, going through some of these procedures, it was like the guilt really kicked (crying) in on like, you didn’t do enough, you gave up too soon. He should still be inside (crying harder).

She continued on later in the interview about how she felt deeply responsible and selfish when seeing her son in the NICU.

…which is an impossible decision in the moment like, and eventually we were going to get up to the point where it wasn't even going to be my decision any more, you know? Like that's the way things were headed. But, but I guess the fact that that I did still have some say in it just felt like, yeah, that I had like made a selfish decision, like I couldn't handle the stress of like being pregnant and like feeling responsible for his well-being anymore. And then, you know, looking at him, laying in the incubator and like, dealing with all of these heal pokes it just felt like…yea.

Lindsay reemphasized her experience of her body failure, this time stressing the personalization of failure: “And then you know the way like your mind works and stuff like, it’s even like you… my body. Then, just like because I didn’t (stressed words), I (stressed) couldn’t do that, you know? I, um, you just like personalize it all like so much.” Ellie described the intense and long process of navigating her sense of failure and responsibility about her son’s wellbeing. She shared, “So I think that’s the thing about NICU moms, and like just you know, being a woman in general is like you just can’t even know what that guilt is like to (crying). To
feel like you failed them, and everything that your baby goes through is because you weren’t able to do the one thing, you know?”

**Despair and Hopelessness**

This subcategory of the “Deep Dark Battle” is about the desperation and hopelessness the women began to experience as their infant remained in the NICU. This part of the downward spiral is when blame and attack become focused outward. Brooke highlighted needing her daughter to be home. Despite not wanting a specific medical procedure, she eventually agreed to have a feeding tube placed in order to take her daughter home. She shared,

I finally like opted for it [G-tube] because one of the nurses that we got really close with was like, ‘It’s gonna get you home, you know, and it’s gonna get you out of here. And then you can get to figure out your new routine, you know?’ And it was to the point where I was like she, she would be better with us at home than in the hospital, and so we opted for the G-tube placement.

Up until this point of the Deep Dark Battle participants have been saturated in blaming themselves or taking ownership for their infants’ admittance into the NICU. As the women navigated their sense of failure and shame, finding no relief or resolution, they shifted blame back outside of themselves and towards the larger system. This shift emerged as desperation to get home and rumblings of frustration with the final steps until discharge. Andrea described her awareness of desperation feeling stuck and restricted by the system. When referring to the hospital, she stated, “I don’t think this is a prison, like am I allowed to leave whenever I want? And you don’t really know the rules anyways.”

**Desperate to Get Home**

Participants described feeling acute despair to get home with their infants. This despair often occurred as infants were approaching what women described as “the end.” They discussed feeling trapped and stuck, questioning if they would ever get to leave with their infant.
Abby described begging for information that she would get her children home by Christmas and her emotional distress of learning that discharge then was unlikely.

I want them home for Christmas like I just want them home for Christmas. Is that possible? Is that doable? I would have some people like giving me false hope and be like, ‘Yeah, yeah, absolutely.’ And then I had some people like, ‘No, it was probably going to be like two months that they're here.’ And I’m like, ‘What?’ (surprised face). So Just hearing those words. It was so like crushing, you know, and frustrating.

In another part of her interview Abby passionately described her despair to get her daughters home.

Feeling like, like there are so many times where I'm just like, ‘I want to just take these little hugs tags off my babies and walk out of here.’ And, I can't do that. I, it will be considered, you know, kidnapping. But there was so many times where I was so tempted, and I just wanted to, excuse my language, but I just want to say ‘fuck this! I’m just done. I'm done here. I'm done dealing with this. I just want my babies home and safe with me (crying).’

Ellie described a similar feeling, adding textured language to the distress of the experience. She shared, “Yeah, it was, yes, it was really tough there towards the end. Like I just felt like we were like stuck in purgatory. We were never going to get out of there. We were never going to get off the IV.” Lindsay also articulated her despair wanting to get her son home. She outlined a time when he appeared to be getting well, but was not well enough to be discharged from the NICU:

Probably, the hardest time through . . . the NICU story, so like maybe trying to get the end toward to discharge. I’d say that once [Seamus] started to be doing better where he could nurse a little bit…He was like starting to nurse. We were like pulling back on the tube feeding, and he was, you know, off the CPAP, but he still like could not drop the oxygen. But he was doing better, you know, and that's where it started to get like really (emphasized) hard for me again, because I really wanted to bring him home. And you look at, and you're like, he looks like a nearly healthy baby. I just want to take him home, and I just wanted to start that, start our life. And wanting [Sage] to be able to meet his baby brother, started to become like this really important thing for me, because I felt like it was a huge shift in his life like this, you know. Crazy change for him. And his family, you know, had changed, and he couldn't even participate, or be a part of you know, meeting him, and I just felt like that was so hard for him. And just for me...
She shared about a sense of pleading with the doctors to gain permission to leave. “So finally, I think I was just like desperate, and there was um (pause), I really want to get him out. I think we were like begging at every morning when we'd see the doctors.” Lindsay discussed a growing sense of despair that stemmed from the pressure to be doing more for both of her children and to have her family all together. She vividly described the anguish of her situation.

Yeah, Yeah. So… And that was, I think that that was what really, really, built and built until when I said I felt like desperate at the end. You know it was like I just couldn't take all that pressure. That was what it was really was like this feeling of like… But Um, yeah, it was. I feel like that all of that just like in there was what finally just really contributed this feeling of like, where we were just desperate. Like ‘What do we have to do to get him out of here?’ (loud voice) You know we cannot, you know, take, take another week of this. We need to get this baby home. I Just felt really… Yeah, like, ‘Okay, we, we've been grinding it out, and it's not sustainable. We can't do this, you know, indefinitely, and not knowing.’

She further shared about the peace she felt upon getting home and having her family united: “We just have to be at home. So that we can, I think I did not leave my, when we brought [Seamus] home, I think I didn’t like leave the house for like ten days or something, you know? Yea, you know. I was like. ‘We're neessting like, truly. Yes, and that was, felt so good.”

**Personal Despair**

The stories from participants also revealed an experience of personal despair that developed for women while having an infant in the NICU. This despair represents women’s sense of hopelessness and inability to continue on in the emotional state that they were having to withstand. At times, the despair was so great women referenced disappearing and suicidality. Abby stated clearly “And I mean, there were times where I was suicidal. There were times where I’m like, I don't know if I can make it through this. I don't know if I can do this.” Brooke described her need to separate her thinking and roles in order to continue functioning in a survival state: “I needed to just kind of compartmentalize, to survive in those moments, because I
feel like if I hadn’t done that, I would’ve curled up in a ball, and like not wanted to be a part of anything.” Brooke related her experience in to the NICU to other major trauma she had lived through. She emphasized the fact that it was her infant’s suffering that made this experience worse in comparison: “And I mean, like I have been through life. You know what I mean, like my Mom died when I was young. I was raped shortly afterwards. Like we have, I have gone through crazy experiences, but like this… and I mean, obviously it's your kids, but this is like the worst (emphasized), you know?”

**Escaping the Spiral**

The participants of this study identified coping behaviors that supported them through their time in the NICU. Despite these women’s intense experiences of having their infants hospitalized they discussed accessing help to escape from the downward spiral of the experience. Some of these supports and coping included family, friend support, counseling and finding ways to make meaning of their experience. The subcategories of this theme include: Avoidance and Distraction, Family, Social and Online, Attuned Care, Counseling, Mom Pride, and Spiritual. These subcategories are avenues from which women found and drew support during their time in the NICU. Brooke identified taking it moment by moment in order to support herself through her NICU journey. She shared, “I mean, it was kind of um, kind of one of those things where I just had to…It was like one moment at a time. You know, I had to compartmentalize a little bit.” She also identified,

We are just, we're so blessed we're so blessed. You know, just with the support that we had with friends and with my job and with our families (support). You know we live really close to my husband's family. They live about ten minutes away in my dad and his partner live, a few minutes away as well, and my brother's close by, and so we have just a really good web of support that was like, really integral for us.

**Avoidance and Distraction**
Several participants highlighted one of their coping strategies as engaging in behaviors which helped them distract, and at times avoid, the situation they were in. Brooke described this tactic: “I felt so often that I was dissociating in my time in NICU. So, I would try to immerse myself in other things. I would be constantly reading and constantly like trying a lesson plan. And, um trying to like, organize. And do, you know?” Jessie also talks about being able to turn away from the trauma she experienced, and not recognize until later the massive event she persevered:

I wasn't like, I didn't focus on the trauma that I had just experienced, you know, because, until maybe later. And then it was like, Oh, my God! Like this, like wow! And then I start processing maybe months later, and I’m like all of these things happened. Where was I? Why wasn’t I a mess?

Andrea described coping by staying busy and distracted while at the NICU.

I don’t know, I just pushed through it. I mean, I, I watched a lot of Netflix on my laptop and read. And at the time, I was going through some further education, I was getting my CPA license at the time, and so I kind of was just trying to entertain myself with that, keep myself busy and mentally engaged, I guess. Work is, I really love work. And for me, yeah, I would just I know not a lot of people say, but I love my job. And so, it was kind of nice to sort of escape the NICU a little bit, focus on my education and sort of just keep my brain engaged.

**Family**

Nearly all of the participants described their family as supportive to their NICU experience. For some women this was their spouse and for others their extended family. Here, women described finding support in a variety of ways. Some described receiving emotional help from family, while others articulated not relying on family for the emotional support they needed. A few women described finding support from logistical support their families offered. Abby shared, “I think my biggest support was my mom (pause) being there and helping me... yea...So I mean she (mom) was my biggest support, and I appreciate everything she did for me.”
Similarly, Ellie shared a story about how her mom offered her support in the darkest days of her NICU journey.

Obviously, my mom and my husband, my parents just moved down like two months prior. And thank goodness they did, because yeah, they were such a help. Yeah, there was like one day where, I don’t know. I just was like pretty down. And so, my mom was like, ‘Why don’t we go? Like I’ll pick you up from the hospital, we’ll go grocery shopping.’ You know, there was a little fridge in the room like it stopped that just kind of trying to brainstorm ideas of like, ‘Let’s get you out of this hole.’

Brooke shared how having her family in close proximity was an important aspect of support to her. She described, “You know we live really close to my husband's family. They live about ten minutes away. My dad and his partner live a few minutes away as well, and my brother's close by, and so we have just a really good web of support that was really integral for us.” Lindsay described feeling grateful for the extended family she had available to her and to help with logistics with her older son.

I felt like oh we are so lucky because (pause) um, we’re both from [town], and both of our families live here. And, we have lots of friends. Like, close friends, childhood friends. Because I felt like I was like shuttling [Sage] around to different places for people to watch him, like piecemaking child care for him while we would go to the hospital and stuff. And I had a lot of, you know, grand, between grandparents and aunts and our close friends that there were people for us…And so again, I would go like back and forth with just these feelings of, ‘I feel so bad’, or ‘this is so hard.’ And I’m having to ask all this of my friends and my family, and then being like, ‘I'm so lucky because I have friends and family here that I can ask for this, and I can see the rest of my family.’

Lindsay also identified her husband as being a great support to her. She shared that she felt that he could relate to her. She stated, “and just like, be my sounding board, because, like, just like, listen to like how I was feeling about all of that, you know, and know that probably he, you know, could understand the most of anyone.”

Social and Online

Although the women of the study experienced a general absence of social support in the NICU itself, some participants sought support and connection beyond the NICU walls. One
participant described making a close connection in the NICU while others discussed seeking a sense of understanding and universality through social media connections.

Abby shared her experience with this:

So, the only thing that I, I did for me because I wasn't getting it there is, I joined a Facebook group that was for NICU Moms or NICU parents. I was also in a Facebook group for twin moms, and so I shared my story on there, and I was just crying. And so, when I felt like I needed to vent or talk, I would just write like an anonymous post on there, or whatever. And people were so, so, kind and so supportive. And they're like you got this mama like you can do this (she begins to tear up, voice fades) … (still crying, pause). It's like those are from complete strangers that I've never met before that are on the Internet. But you know, we're all moms, and we're all (pause) yea, struggling and going through the same thing or something similar, you know, or could imagine going through something like that.

Andrea also described using social media as a way to connect with old friends who were also navigating having an infant in the NICU.

I did find myself reaching out to, and actually connecting with a lot of people…reaching out to people who, you know, I went to high school with or grew up with, or was a cheerleader, played soccer with, who had children in the NICU or were going through the same thing. I actually reconnected with a ton of people, who I otherwise wouldn't probably, you know, it's, you follow each other on social media…And reconnecting with a lot of people I probably otherwise wouldn't have.

Brooke described making a lifelong connection from the NICU.

During our NICU time we got really, really close, uh, or we had a very good friend, named [Katie], uh, and her little one [Sloan] and [Josie] and me, and we would always just say that they would just be best friends, because um, they were about the same age, and um had all about the same stuff go wrong (laughter).

**Attuned Care**

Participants of this study also described finding support from staff offering attuned care. Participants discussed several ways they experienced attunement from staff. Women reported feeling particularly well cared for when their infants were being taken good care of by the staff. Andrea shared, “I've nothing but amazing things to say about all the nurses and the doctors and
they took such good care of him.” Ellie also shared her experience of attuned care with a specific Doctor whom she felt put in extra for her son’s wellbeing. She shared,

There was one Neonatologist that really, for whatever reason just made such a difference. I just connected with her. And yeah, I just felt like she went with her gut instinct with [Tom], and kind of discovered some things that you know other Neos had not brought up.

She later described an interaction when this particular Neonatologist was able to see her anguish and meet her in the midst of a dark struggle with words of encouragement. Ellie described the support she felt,

It was nice because it she [Doctor], she was like, ‘I get it. I've been there.’ Like, ‘You did not fail him.’ Of course, she reassured me about all of the things and you know, pointed out all of the things he was doing well. He’s gonna get this, you know, like she just, it was a pep talk. Yeah, really…

Andrea also had a staff connection she found support and comfort in, given how care for both herself and her son were provided.

I had one friend, I actually had, we know her through mutual friends, and she's a nurse and so she was probably like, one of, I mean, she's amazing. And so she was in kind of the shared room at first and I saw her and I was like, ‘Oh my gosh,’ and, you know, we got to talking. And she was, I feel like she made, I don't know if it's just her personality or if its, because she knew me, but I feel like she always was like constantly checking in on me and checking in on [Sam]. ‘I don't, I'm not scheduled with [Sam] today but like, I just came in to like peek on him and make sure he was okay, and like you're okay.’ And I feel like she was probably one of the like, my biggest support pieces.

Staff Support for Relational Health Between Mother and Baby

Another aspect of attunement women discussed was when staff supported the relational health between mother and baby. All of the participants described finding support and ease when staff was able to kindly facilitate connection between them and their infant. Jessie discussed clearly that she experienced ease when staff were positive with her son. She stated,

But we did have like significant, like a couple [nurses], probably I'd say, maybe like two or three that were really supportive and kind, and just really good with him. I think that's what made it like easy for me.
Abby identified that the more the nurses accepted her, and invited her into the maternal role, the more she felt cared for and seen by them. “The nurses up there were extremely kind, and were very much like, ‘Oh, here you want to hold her? Here, let me get her out for you, here,’ you know, like very much more wanting me to be more involved.” Later in the interview Abby offered another example of a specific nurse she felt connected with who offered her the opportunity to further engage in caring for her children. Abby expressed experiencing connectedness due to the staff’s understanding of her desire to engage in her role as mother. She relayed this story:

So, she would set up the whole room for me and say, ‘Okay, just let me know when you're done, and I’ll come hook them back up.’ And so, I got to [bathe the babies], and, you know, feel like I'm actually being a Mom.

Attunement was also felt when staff provided practical ways for the women to feel close or connected to their infant. Lindsay described the effort that her son’s nurses put into Christmas Day, when they were separated. She shared, “The nurses, and everything like, they did this adorable little like photo shoot, and they knitted him this little like elf type hat and gave us the photo in a frame. It was the sweetest thing.” Similarly, Abby described how a specific nurse she felt connected to offered a deep sense of care by integrating her daughters into the family’s holiday:

I had one nurse who helped me on Christmas day when I was there by myself. I wanted to take like Christmas pictures of the girls, and so they gave us like one of those big, huge stockings, you know, and I can fit both of the babies in there, and she helped me set it all up and do a little photoshoot on the bed in, in the room, and she helped me take pictures and stuff.

Lindsay also reported feeling deeply cared for when the staff would make attempts to integrate her oldest son into the life of their newborn, working to bring the family into deeper connection despite being separated.
They would like, ask us about [Sage] (oldest son), and then, like helped us do little things for, for him like had ideas for. . . Oh, well, you know, we should trace [Seamus’s] hand and bring that to, and then you can bring that to [Sage] . . . and um. . . And I remember thinking that's such a wonderful idea, ‘Thank you.’ So that was the, probably like the number one, and you know, biggest support that I had.

Several participants reported staff offering care and kindness specifically to them. They identified this kindness as a sense of support and comfort. Lindsay gave an example of staff putting in extra effort which felt supportive. She shared,

And they, it was, you know, kind of nice, actually, because, [Dr. X], and then and one of the other NP’s, and a nurse, all came to my room over in labor and delivery before I had my C-section, and they kind of like told me a lot of stuff to expect…I did think that was really kind, and just good practice, you know, for them all to come and talk to me.

Brooke spoke highly of several specific staff that she was surrounded by. She identified feeling staff was alongside her and her daughter throughout their journey.

I would just say our nurses were a huge support, like we got really close with [Lisa] and [Lacy]. We just have, I hold them to such a close, such a close place in my heart. Really, truly, I call them her fairy Godmothers, you know, because they were just such a huge, huge part of our life…saw us in some really dark times, and really great times.

Similarly, Abby experienced being cared for personally by the nurses. She reported feeling this by one particular nurse would often see a need of hers and respond:

The nurses were great. I was able to, when I was there by myself, and I didn't have my mom with me, one would come in and say, ‘Oh, do you want me to help you?’ Or you know I could talk to them and say, ‘Yeah, my mom's great, but I’m just really struggling, and I’d start crying to a nurse, and they would listen’. . . So, we really had that good bond and connection. And then, so I would request that one specific nurse, because I just loved her, and you know. And then it was hard when she left. She was a traveling nurse. She left, and then I feel like, oh, now I’m losing one other person that was there for me, and supported me, and you know, help me so. That was hard (begins crying…pause).

**Trust in the Medical Support**

This property of **Attuned Care** demonstrates how participants established confidence and security in the medical care their infants received from doctors and the nurses. Nearly all of
the participants felt reassured by the quality of care and the competence of the staff towards their infants. Examples of this theme from participants Ellie, Andrea, and Lindsay demonstrate how they view quality care. Lindsay shared in detail about the comfort she found in knowing that the staff was competent, skilled, and in-tune with her son’s needs. She described feeling connection to specific staff, and soon realized that she could trust the medical team as a whole:

Well, I felt like the nurses there were pretty special, and I was so impressed, I was so impressed by them. And, you know, totally different than even like the doctors. And I felt, of course, that they’re so skilled and knowledgeable, and everything…Then, I started to realize that we were in good hands, no matter what.

She continued on, reiterating her experience of the staff’s competent care. She further emphasizes their skill, way of being, appropriate levity, and overall attunement.

But for my experience I felt like they were really good. Like a special breed, a special breed. Just yeah, the things that they can do, it's pretty impressive, and that was reassuring. They can like intubate a tiny tiny human. And they would, you know, I felt they just had this way of being you know. . . There was sometimes like levity when it was like appropriate, um, so just they could like talk to you about other things or the way they helped.

Ellie also identified feeling trust in the medical care her infant received. She shared,

I was okay in the moment, like I really was. I honestly just remember feeling relieved. Like, ‘Okay, I got him here. It's not the finish line, but he's in good hands. I trust the nurses I trust the doctors’…I didn't... I just remember feeling so much relief.

Andrea also spoke of her experience trusting the care of her infant. She stated,

I felt really confident in the NICU. Of course, I feel like I was there enough. To be honest…I was there all the time. So that, you know, and the nurses were really great. I mean, we were very lucky that nothing ever happened when we weren't there.

Counseling

Several of the women in this study identified counseling as a main source of support along the way. Abby and Ellie both shared their gratitude for counseling and their continuation of trauma therapy post-discharge. Abby reported, “I reached out to my, on my own, and found
my own counselor, and did counseling appointments over the phone.” Ellie shared her gratitude for the mental health support she had.

Well, I (pause) I was really grateful that I was like already plugged into counseling like even during pregnancy I had been going once a week. And thank God, because I'm too... I cannot imagine, like having to go through that again without having like my weekly counseling appointment. That, was just, you know, even if it was for an hour every week where I could just kind of talk about everything…. I don't know... counseling probably stands out as like the biggest.

**Mom Pride**

An aspect of coping that became present as women shared about their NICU experiences was the pride that women held for their infants. Despite the intense struggles that each infant faced and the consequences the mothers faced due to these struggles, women continued to find and share the positives of and the exceptions about their infants. These exceptions offered women hope for their infants, and support of being able to move away from their emotional downward spiral and place their focus back on their infant in a positive way. After describing her despair and worry for her infant’s wellbeing Ellie stated, “But yeah, he turned it around.” This statement offers her son a sense of ownership and success. Brooke shared a similar sentiment about her daughter after seeing her and rooting for her despite her extremely premature arrival. “And then they pause by us, on their way into NICU, and we were able to see her, and she was all wrapped up, you know, in the plastic and everything, and she was great!” Brooke summed up her sense of pride that her daughter was strong enough to not need to be intubated. She explained “it's just a miracle from the beginning, she never required an intubation. She was only on CPAP.” Jessie described first seeing her son and the pride she felt for him coming out long and strong,

He was like seventeen and a half inches long. Not even kidding. Yeah, with these massive hands and feet. Yeah. So I, when he came out I didn't have my glasses on, but I
could see him faintly. I was like, ‘Oh, my God! He's so! He's so big,’ and then they're like ‘He's three pounds.’ and I’m like, ‘Oh, but he looked huge.’

Ellie expressed her pride by highlighting how quickly her son transitioned off of CPAP support and her experience of delight when clearly seeing his face. She shared,

Luckily he only had to be on CPAP about for twelve hours, and so the next morning they weaned him off of it, and he just stayed off of it. That was the first time I was like. ‘Oh, my gosh! My baby!’ I could see his face, you know…And then I think I finally felt that like, ‘Oh, this is what it feels like,’” you know. And so it was a little bit delayed, but really pretty quickly compared to…

Ellie expressed pride as she shared about her experience of bonding with her son without medical interventions obstructing her view of him. As she described, “Oh this is what it feels like” it became clear that up until that point she had not experienced the connection and bond she had hoped for. Jessie described her pride in her son and how she felt he brought a calm to the experience. She relayed,

They’d be like, ‘he's such an old soul,’ Because when he'd lay there he would just look at you and stare at you changing his diaper, never cried. He was just there, taking it all in. It just made everything so easy in the NICU.

Spiritual

Several participants described finding support in their spiritual systems, and in some cases through what participants explained as divine intervention. Women also discussed that they were able to make meaning from some of their experiences during their infants NICU stay.

Making Meaning

Participants described times where they felt there was meaning-making in their NICU journeys. Brooke reflected on the difference between her first postpartum journey, during which she contemplated dying by suicide, and her NICU journey, sharing that her daughter’s hospitalization gave her a reason to live. Brooke shared
But with [[Josie]] I knew that even with the post-partum depression that I had and then, like post traumatic right? Yeah, from her NICU experience that like she really, really needed me, you know, like she really needed me, and having lost my mom at a relatively young age, I know I didn't want to do that [Suicide] to my kids, because that would be a lot. But…And maybe that's ultimately was God's reasoning, right? Like He knew that I couldn't handle postpartum with her. I don't know, so I needed maybe those extra support, some extra reasoning to stick around…

**Spirituality**

Several participants identified that they had a belief system from which they could draw support. Jessie and Brooke were able find reassurance that they were on a path that had been paved before them. This spirituality allowed women to move away from the ownership they may have felt regarding their infant, handing the broader perspective to something greater than themselves. Jessie explained a spiritual experience which brought her solace.

Something like spiritual that happened for us while we, the day that I had gone, had, had delivered him. Um, we had on, like, you know, the board, and like the delivery rooms, and like they write the nurses names. Well, our nurses’ names were Kathleen and June, and those are both of our, like myself and Oscar's dad's, maternal grandmother's names that have passed away. I’m like dead serious. And so, they made their presence known…And so in that moment, I knew we were meant…not, you know, there was a reason why he was being brought to us, and so I think for me it was, I knew, like just that it was…. This is how things were supposed to be.

Brooke also discussed how her faith supported her during the journey that she and her daughter experienced.

I think my biggest thing is just… I'm a very, very spiritual person. Um, I just think the biggest thing is just uh, just how blessed we are, you know. With all of the things that could have gone wrong, and all of the times that she really should have died, you know, I mean from the beginning of her life. It wasn’t expected, and so, I just hold so tight to our faith, and knowing that, like she has a job on this earth, and she is here for a reason. And like she's already so feisty, and so they always say, like the spiciest kids in NICU do the best. And she is just a testament to that, you know she's just so, so spicy, I mean, so sassy and so smart.
Jessie also described how her spiritual belief system supported her and offered peace. “and we've connected pretty significantly with like signs of you know, people just letting us know that they are present. That they're here, and then also just the name that he carries, you know.”

**Post Discharge Experience**

Unfortunately, the NICU experience is not one that ends abruptly post-discharge from the hospital. It is a journey that the women of this study describe having to continue to navigate even once home. Throughout the interviews, participants reflected quite often that their NICU experience continued on past discharge. The participants described both positive outcomes and some of the emotional consequences they had to face after leaving the NICU. Post-discharge women reflected on their desire for longing and connection during their NICU stays, and outlined what they wish they had throughout their NICU journey.

**Post-Discharge Anxiety**

Women articulated the deep anxiety they experienced after their infants were discharged from the NICU. They expressed concern about possible harm coming to their infant and continuation of concern and medical follow-up for their infants. Andrea shared about the immense anxiety and acute stress she deals with. She communicated about that ways she has adapted around the fear of harm coming to her son.

I mean, I definitely suffer from anxiety now. Post anxiety for sure. Yeah, I like, I don't think, I think it's, I talked to a lot of parents about it. And it's, you know, you have this innate fear all the time of like something happening to your child and you get these cr.., I mean, the cr.. your, “what if a car pulls out, and it's …” and it's just like these horrible thoughts you have, and I’m like, it’s like that panic feeling of oh my gosh… what would I do and now I’m like a crazy defensive driver. Like you have like, these bizarre things that happen I think, because you’re obviously want nothing to ever happen to your child. Again. Yeah, exactly. And yeah, I’ve definitely struggled a lot more with the post anxiety of something happening to Sam.
She continued on sharing about her distress specifically surrounding his breathing due to several episodes in the hospital and having to come home on oxygen. She named the intense panic and trauma that she and her husband continue to work through.

But I mean, I think just that after the fact of, you know, he came home on oxygen, and so the breathing thing for me is, I still to this day… Yeah, he’s 18 months old, and I psychotically will check the monitor to make sure he’s still breathing. My husband’s the same way, and I’m like ‘Are we just traumatized from him coming home on oxygen and, you know, the monitors going off occasionally at night, and just kind of like…The PTSD, Yeah. And so, I think, yeah, it’s just created sort of anxiety in both of us that we still have no idea, maybe it'll go away.

Andrea confessed to finding security in at-home medical devices in order to provide information about his oxygen levels.

Once we got his, you know, like oxygen reader removed from the home, he had the pulse ox on and all that and we were very lucky to have it in our house for a long time (laughter). And I think I use that as like, my security blanket of knowing, okay, well, if it goes off, if it doesn't go off, he's fine. If it does go off, like something's wrong, or I need to check on it, I can fix it and I'm alerted. And so, when that was taken, when we had to give it back, obviously cause its hospital equipment. My husband, I was like, (changing track to talk of herself) I'm not, I can't I'm not sleeping. I'm just like, watching the baby monitor constantly. And I mean, he's right next to me anyways, at the time. And so, you know, it's like constantly just reaching over and like putting your hand on them, making sure they're still breathing, and I'm just like, I can't do this anymore. And so, we ended up getting an owlet sock, to like, try to help me with my anxiety, which helped and worked great and used it for, I want to say until he was about probably a year or so.

Abby also described the intense worry she felt about her daughters' health after being discharged.

She too found medical supports to help ease her concerns.

We had to do one of those Zoe heart monitors on her for two weeks and that came back with a couple abnormalities, so we had to continue on with the cardiologist. A couple of times they did another echo on her, and then they said that her heart was a little bit enlarged for her size. And then, the last time we went back they did say that they didn't notice any more arrhythmia. And so, it looked like she had grown out of it. And so, they just want to see her back once a year. Um. But in the meantime, I at home, I monitor her heart rate, and I check um. I check it with a stethoscope. But I listen, you know a couple of times a day just to make sure it's where it should be.

**Post Discharge Reflections**
Even with experiences of support and attunement, women shared about their desire for increased support and connection during their NICU stay. One way this emerged was in participants generating narratives and suggestions, after discharge, about what they believe they should have had, or could have had during their experience in the NICU. Participants expressed a desire to have mental health clinical support which could check in on their own wellbeing. Women shared their hopes for having support with basic daily tasks such as access to food, holding support, and chances for respite from being in the hospital in order to take care of themselves. Participants also identified the need for opportunities to connect with other mothers who shared in understanding of the NICU experience. Abby clearly stated her desires and the expectations of support she longed for:

But, I feel like the social worker should have checked in daily. They should have came up there and said, ‘How are you doing? What do you need? How is your support at home?’ You know? ‘How are you feeling up here? Do you need more support while you're here? Do you need somebody to sit in here and hold a baby while you go to the shower?’ You know? ‘Do you need us to bring your meal up here for you?’ They would give me meal vouchers, and stuff sometimes, but that's only if, they remembered. And then I felt guilty about asking.

She also discussed her developing ideas about possible support to future NICU parents.

So, I feel that, I definitely think that they should have some type of program, even if they had volunteers who went up there and said, ‘Hey, we'll volunteer to like bring a breakfast in, or just bring it up from a from downstairs, and just have it set up for you,’ you know? And then you could come in and grab something to eat when you needed it, or, you know, have that little group thing, and they say, ‘I understand if you can't make it at this time, but just know that a social worker will (emphasis) be in this room for you if you want to come in and talk. Or, if you want to meet another mom who is going through what you're going through’...

She further noted the massive need she sees for connection and support to be built into the medical system. As she shared, she again noted some of the area’s women can use support during such an intense time. She stated,
Not everybody has a support system, not everybody has a mom who can come up there and stay with you. And I feel like that really needs to get looked into. Like I said, do a volunteer program and have somebody just be your buddy up there, or be like extra, like a grandma to go, or a mom to go, you know? And just be that person ‘I’m here to support you and what you need. I’m here to go get you lunch. I’m here to, you know, like hold a baby or feed a baby if you need to sleep.’ Have postpartum doulas available there.

Several of the participants identified their longing and need for someone to offer them support. The support they desired was physical (offering food and drink), but also emotional and social. Participants articulated their yearning for someone to check-in on them during their NICU experiences. Ellie shared, “And I, it’s like I needed someone to take care of me because I wasn't doing it.” Abby identified the expectation and need for easily accessible emotional support, “No, I should have had a counselor. I should have had somebody available to me. I should have had that support.” Andrea discussed the desire for someone to reach out to her, offering both check-ins as support and time to connect and share about her experiences.

Some sort of more communication would have been really nice, and like even someone just being like ‘How you holding up today? You doing okay?’ …Yea, you know, and even if it was, you know, um, I read in a lot of hospitals that they have um like professional snugglers and I’m like, I don’t want that for me, I don’t need someone to snuggle me, but someone that just comes in and is like ‘Hey do you want to talk for like 5 minutes?’ Like, ‘How you doing? We could go grab a coffee…’ and I think too like in the beginning it might be a little uncomfortable, but I feel like most NICU parents are in for you know, more than just a few days. And so, I think just having that person where it's kind of a once a day thing, like, ‘Hey, you, you good?’ And then eventually, you get to the comfortable point where you're just like, ‘I'm not good.’ Then just having, you know, feeling a little bit more comfortable over time.

Andrea continued on, “I mean, ultimately, it's not a massive NICU. So, I feel like it's an easy, not an easy job, but I feel like it would be feasible just to have one person just being there to, like as a point of contact, to just you know, saying ‘Hi, hey, I'm here if you like, need anything, you know, that's what my job is.’ Would be super, super helpful.”
Women also discussed their desires for connection with understanding others, including other moms currently in the NICU. Abby stated:

> It would have been great if they had, like, a little meeting room or something for the moms to like, get together and talk upstairs in the NICU and, and talk about like their struggle…like ‘every morning at 10:00 we’re gonna have just a check, that morning check-in with you moms to see how you guys are doing, and so you guys can meet each other and have somebody to talk to, and support you, who understands and who's going through it. And then, or every evening we'll do something, too, you know, like where you guys can come together and just be that support for each other.’

Andrea also identified her need for connection with understanding others: “And almost just have someone that can at least, maybe someone who has, who’s been through it in the past or something, and can just sort of have you know, just some conversation.” Brooke shared her similar wish to have had more connection with other parents of the NICU in hopes of creating opportunity for universality and understanding:

> And it was one of those things where I was like, ‘Well, maybe this is something like I should start. Maybe we should just all go out to eat, and then we can go back to NICU’…But I really think just some time with fellowship with other NICU families would have been huge, and especially families who had been there, right? Would have been really beneficial to have just even like a monthly or every other week, kind of get together where we could sit and talk and cry, and do all the things. You know? I think if anything that would be the most beneficial for someone who doesn't accept help very well (laughter).

Brooke later shared about her ideas of creating a formalized way to support other women in the way that she desired to be supported: “Or maybe I can start like a nonprofit, and I can be here to help counsel Moms at NICU, and maybe like all of these things, and just like talk about my experience with them…. Sit with them as they cry, whatever.”

**Post-Discharge Experiences to Explore Further**

Several aspects of the post-discharge experience began to emerge that need further exploration in second-round interviews. Some of the participants shared about their experiences
of being post-discharge and feeling pressure to “be okay”. They expressed the challenges of continuing to have their emotional needs overlooked. Finally, Jessie and Brooke spoke briefly on the intense continued medical follow-up that their infants faced after being discharged.

Abby shared about how she found comfort in telling her NICU story in the interview process. She highlighted the continued absence of support she felt as she began sorting through her NICU experiences after discharge. She shared,

Because, to be honest, I haven't shared this experience with anyone. I haven't been able to tell the raw, ugly truth about it, you know, I had to just say like, ‘Oh, it was great. Oh, you, you know they helped so much, and you know the girls are fine.’ You know that we just pretend like everything is okay, and I've never ever spoke about it, (pause) so I feel like it…It was like(paused) healing for me.

Brooke gave a clear statement about feeling misunderstood and bypassed after discharge.

And then, once you're discharged from NICU, it's like you're dropped off the face of the earth right like, people think that you because you're out of NICU everything’s fine, right like. Oh, they're good. Yeah, they're done now, right They're a normal baby, but it's like no, they are not.

She continued on highlighting the continued social messages to be “okay” despite having endured an excruciating experience with her daughter and continued concern for her health.

Kind of trying to rediscover my identity, right? So, for 110 days I was a NICU mom. Like that was my job. That was my sole focus, and then we get discharged and come home, and we're so happy to be home and but now I have a new identity as a mom with two, but not only a mom with two and a mom of a medically compromised baby with medical needs. And so, we have appointments with dieticians, and we have appointments with PT and OT and speech, and, and all of these things that we're trying to juggle, (sigh) and it's just, you know, when people will say, Well, how are you? It's like, Oh, I’m great! But I think, that we're, it feels like we say that we're fine, all of these things. But if we say anything other than what's expected right, the expected is to say that we're fine, and that we're so happy to be home, right? If we say anything other than that, then what? (pause) Then we're not grateful right? I think we have those social expectations to say that, like ‘everything's fine’.

Jessie shared about her experience post-NICU as, “I feel like our circumstances were super rare like, but I had like a lot of like follow up care for sure like that was pretty consistent. Yeah.”
Summary of Findings from Round One

First round interviews provided detailed and rich descriptions of what women experience while navigating having an infant in the NICU. The data revealed the intricacies of what women are juggling, while also giving insight to the internal turmoil they are enduring. Six themes emerged from first round interviews: Entering the NICU, The Forgotten Mother, The Juggling Act, Deep Dark Battle, Escaping the Spiral, and Post-Discharge Experience. First round analysis left me with further questions regarding:

1. Women’s experience with the Acute trauma – fear of death.
2. What are the protective factors, if any?
3. How have you made meaning of this time? Integrated with your identity?

Second round interviews were conducted in order to solidify and add texture and refinement of the themes identified.
Chapter IV: Second Round Analysis

Chapter IV is the continuation of identifying and outlining the rich details of the experience’s women navigate while having an infant in the NICU. In this chapter, themes of first-round data were further developed and clarified via second-round interviews and data analysis. Second-round interviews also allowed for the development of new themes.

Review of Procedures

I contacted all six participants from first-round interviews to participate in a second interview. Round-two interviews occurred three months after the first-round of interviews. Interviews were conducted via the Zoom platform and lasted between 20-60 minutes.

I implemented a semi-structured interview process for round-two interviews, asking the following questions to clarify round-one themes, expand first round data, and seek saturation:

1. What thoughts have you had since our last interview? Do you feel there is anything that is important to add?
2. From first-round interview, women began to touch on the idea of the ‘pervasiveness of death’ they were immersed in. Can you tell me what it was like for you to be in such close contact with the possibility of babies dying?
3. How have you integrated your NICU experience into your purpose or ways of being in a holistic way?
4. What would you tell other NICU moms on this journey?

I employed varied follow-up questions depending on the participant’s response to add depth and clarity. I transcribed the interviews and began data analysis. Second-round interviews helped to confirm existing themes and clarify subcategories and properties of these themes. The new data expanded upon women’s experiences with The Pervasiveness of Death. This aspect of the data became much larger and developed as a theme rather than a subcategory of The Deep Dark Battle. The subcategories developed within this theme are: Fear of the Unknown, Preparing for the Worst, and Self-Preservation via Compartmentalization. The data from second-round interviews also clarified women’s experiences with post-discharge. Post-Discharge –
Integrating the Deep Dark Battle, expanded to include subcategories which detailed women’s experiences with trauma, continued guilt, ongoing medical complications for their infants. This theme also developed further to include women’s positive reflections of pride, their desires for understanding and with offering to future NICU moms.

Data Analysis

Like first-round interviews I conducted three rounds of coding with each participant transcript. I first began by reading the transcript to gain a whole perspective of the interview. Next, I engaged in the initial noting of each transcript using a line-by-line approach with three separate perspectives. The three areas of analysis included noting descriptive comments, linguistic comments, and conceptual comments (Smith et al., 2009). Again, I noted and coded key-words, experiences, or events that revealed participants perspectives. Next, I noted all linguistic comments. Again, exploring how women shared their experience with language, sounds, metaphors and tone. Finally, I reread the data and made conceptual comments. From second-round interviews I grouped data into existing codes and developed new emergent themes for each transcript and then across all of the cases.

Experiences of Women Navigating the NICU

Second-round interviews led to the confirmation of the superordinate themes of Entering the NICU, The Forgotten Mother, The Juggling Act, The Deep Dark Battle, Escaping the Spiral and finally Post Discharge – Integrating the Deep Dark Battle. During second-round coding and data analysis a new superordinate theme, The Pervasiveness of Death, emerged as an aspect of women’s experiences of being surrounded and inundated with sick and dying babies. This theme, once an under developed subcategory of The Juggling Act, became more distinct throughout second-round interviews. Second-round interviews asked about the women’s
experience with the possibility of babies dying and opened space for what had been, only briefly touched on by participants in the first-round interviews. Women spoke openly in second-round interviews about the negative connotation the NICU holds, the inherent possibility of death around them, and personal experiences with infants that had died while in the NICU. They also separately discussed their own concern with their babies either facing the possibility of death, but more prominently their uncertainty and fear for their baby’s wellness and future health.

The post-discharge experience became increasingly defined and articulated by data from second-round interviews. Second-round interviews magnified the vast unpacking of trauma that the women of this study had to navigate after their NICU experience. They identified a continuation of their NICU experiences, only now at home without medical support for their infants. They also identified their work to integrate their experiences of the Deep Dark Battle by reflecting on the pride they have for their infants and their own personal strength. They discussed working to make meaning of their experiences by offering advice and support to other women on this journey. Women identified subcategories to the theme Post-Discharge – Integrating the Deep Dark Battle as Post Discharge Trauma, Continuation of Guilt, Continued Medical Complications, Reflections of Pride, Longing for Understanding and Connection, Messages to Future NICU Moms. See Figure 2 for the conceptual map of women’s experiences in the NICU after round-two interviews.
Entering the NICU

In second-round interviews participants reiterated how their experiences of entering the NICU were sudden and unexpected. They clarified how being in the NICU was far beyond their hopes for their birth plan and the dreams regarding their first days and weeks with their infant. The data that women offered confirmed the subcategories of *Sudden and Unexpected* and *Loss of Dreams*.

Participants confirmed the unexpectedness of their babies coming early and needing NICU support. Abby identified how the thought of being in the NICU was not something she considered prior to being admitted. She shared,

And I get thinking, like ‘No, all my kids have been full term, you know. I'll be fine.’ No. It's just the thing about having twins, you know, your body is just ready way earlier than
a singleton. So, I honestly, I also did not think I was gonna have to have them be in the NICU. I thought, ‘Oh, no, they'll be okay, you know. I won't have any NICU time. It'll be fine.’

Ellie confirmed Entrance to the NICU was a **Sudden and Unexpected** experience that was difficult to navigate. She shared how the sudden shift in roles led to her own experience of fear and uncertainty. Ellie expressed:

I think just fear of the unknown. You know I talked about before, he was my first baby, and also he's a NICU baby. There’s just a lot of …it just all was so unknown. Even when I thought, ‘Okay, eventually it's gonna get better, we're not always going to be in the NICU.’ You don't know when that's going to be, or what that's going to look like, or what that's going to entail. Is he going to be on a medication that leads to this other side effect? And so, there was, there was definitely that fear.

Brooke reiterated the subcategory of **Loss of Dreams** that participants reported in round-one interviews. She shared,

It’s also hard to navigate grief through the lens of NICU too… Just having to look through our experience with our daughter, although we're so thankful, we still have a lens of grief that we have to look through that experience with….And you know, when we see like healthy Mamas with their beautiful pregnancies and beautiful babies to term. Coming to terms that it's okay to be happy but still look at it through a lens of unfair, you know?

**The Forgotten Mother**

The **Forgotten Mother** identified in round-one interviews is about the ways that women are looked over and bypassed in the NICU. Brooke confirmed this finding in second-round interviews with a succinct statement, “I mean NICU moms really don't get the support that we need, but we at least have our babies, you know.”

Women also confirmed the ways the **Infrastructure Collapse** was a bypass of their own needs due to the setup of the medical system. In second-round interviews the women added clarification about the ways that open bay rooms added to their distress due to frequent alarms, and situations in which they were exposed to very ill babies. Women referenced their anguish of
watching babies who are sick and suffering as aspects of their experience in the NICU which continue to feel traumatic and haunt their memories.

Abby shared how the medical system attempts to be private and yet, in the open bay there is exposure to sad information about the babies around them. She shared,

And then they [medical system] have the HIPAA thing, and they're trying to keep people's privacy and trying to not discuss each baby's medical needs. But you do overhear things when you're in there, in a room full of other patients. And you know you so badly want to be like, I'm so sorry (crying). You know...

Ellie also reiterated and clarified the ways that open bay rooms added worry due to sounding alarms.

Yeah, Well, it was hard when he was down in the main nursery because he wasn't in his own room yet. And so just like the sounds of the alarms, you know, like you basically just have a curtain. And you're like trying to do this kangaroo care. But then a baby is alarming that...Yeah. And it seemed like they were loud. And so then you're like, 'Oh, you know, is like that Okay? For his ears?'

She continued on, sharing how being in open bay inundated with alarms and sensory input from multiple medical devices acted as a constant reminder of the gravity of the situation and connotation of the NICU. She shared,

Yeah, I think they [alarms] are just kind of, just triggering. Another reminder that, ‘Hey, you're in a medical system,’ even if you’re doing skin to skin with your baby, and you can pretend for a moment that everything's okay, actually it's not, because now you hear this and you know.

Andrea also confirmed the way that the physical design of the open-bay is a part of the

Infrastructure Collapse. She stated,

We were in a situation, I can't even remember if I had told you about it, but we were in a shared room when we first were in the NICU. There was a baby that was next to us, and I mean we only overheard things, from being through a curtain. But you know she was born addicted (sigh) to some sort of drugs. Or whatever it may be, and I think that piece too, I feel like also angers you even more as a NICU parent, too. Because this was a parent’s doing. How could you ever do that? Yeah, just like hearing every time this poor little baby was like coughing, or, you know, sick or crying. And they're like, 'Well, the
WOMEN’S JOURNEY THROUGH THE NICU

baby is crying because it's like withdrawing.' I mean, I think that piece, too. You're just like 'ugh.'

In second round interviews Abby also continued to confirm staffing shortages as she had in round-one interviews. She discussed this as a way that the medical system encounters created increased emotional stress and worry for her. She shared,

And for me the other thing is, I had all kinds of nurses. I never had the same nurse. I did for maybe a couple of days, and I would request her. Then I had traveling nurses and other nurses. I had nurses that would come from different floors and departments, and I'm like ‘Well, do you even know how to do a CPAP on a… like they're tiny.’ And so it was nerve racking for me because it's like, I didn't want to question their skills or their training. But at the same time, I’m like ‘This isn't your specialty. I want the best. I want somebody who has experience you know, working with my child and their feeding tube.’ Yeah, it's not like you're just doing an IV on any person, …And that's an awful feeling, because it's like you don't ever want to make somebody feel like they're not doing their job well, or that you’re not appreciative of them. But there were times where I had to like request not to have a specific nurse come back. I had to show them how to use the feeding tube machine to put the milk on and at what rate to start it at. I’m like, ‘Can I just do it?’ And they’re like. ‘Oh, okay, yeah, I don’t know how to work these machines.’ And I'm like (rolls eyes).

Andrea confirmed the ways the woman’s personal wellness is not acknowledged or addressed as it should have been. Andrea clarified in Second-round interviews how women’s mental health should be addressed more urgently. She shared her disbelief at the current oversight in care for women navigating the NICU, marking another factor of infrastructure collapse.

It's amazing (sarcasm) to me that…And I think we talked about this in our first interview, too, just not really having like the professional help that you need. I think, in the situation where you're… I mean hopefully maybe this this study will, will help, you know. Help that… But it's just kind of amazing [negative amazement] to me that…I know your OB isn't necessarily your provider per se, and they aren’t in the mental health realm of things… but it's like at the same time, you'd kind of think when you’re... I mean your OB knows your baby is in the NICU. So, wouldn't you…is there like no way to just automatically be like, ‘Hey!’ At your one-week post op or post appointment like, ‘Do you want me to refer you to someone just to help you cope? Or even down the road?’ Like, ‘Here's a number.’ Or just something. It's kind of amazing that you're not even offered that. I mean, I remember filling out a… my six-week appointment, like the post-partum, like, ‘How are you feeling on a scale of one to ten? Have you had suicidal thoughts on a scale of one to ten? Or is your anxiety increased?’ and just, you know all those like generic questions that I think they ask everyone. But….
Andrea spoke again in second-round interviews of staff responses and role rigidity that created a bypass in her own care. The story she shared highlights an example in which the emotional handoff by staff was made to someone that was neither prepared or skilled to address the situation. It shows an example of the assumption by the system that the women’s family or support system can hold the level of intense need the woman may be experiencing when in reality, that is often not the case. Andrea shared,

I was in the hospital, I think I told you for like five days, you know, because I tried to stay, whenever the max time was, and in that time, I had plenty of mental breakdowns when I was there. Like, clearly, I was very (trails off)...I had, I think she was just a lactation consultant and nurse, walk me back to the room and be like, ‘Do you need me to call somebody?’ and I'm just like, ‘well, I…’ She was referring to my husband. I'm like, ‘Well, no. That's not going to help.’ I mean he's not gonna really...I feel like, especially your spouse, doesn't really know the right things to say in, in those times, and especially, I think, as like new parents, too. Like he was, he coped a completely different way than I did so...

The Forgotten Mother was confirmed in round-two interviews as women shared again about how they felt overlooked personally and in their role. Women articulated the difficulties they faced in the infrastructure not being set up for their personal wellness, and how their own mental health and emotional health went unaddressed.

The Juggling Act

Participants confirmed the theme of the Juggling Act. They reiterated the pressure to do and be in multiple roles, with multiple pressures that were mentally and emotionally taxing. Ellie confirmed this in second-round interviews when discussing possible advice for other NICU Moms. Ellie shared that she had wished she had spent more time journaling about her experience in the NICU and tracking her son’s progress. As she spoke it became clear to her that due to the intense pressure upon her to perform many tasks at once, that journaling was a luxury she could not sustain as a supportive outlet. She reported,
Actually, now that I think about it, when in the world would I have journaled? I was either pumping or holding him or trying to sleep. Yeah, I don't know. It's easy looking back like, ‘Oh, yeah, you could have done this’ but, my God, I couldn't eat right so like, am I gonna put a pen to paper? I don't know.

Lindsay also reported wanting to do everything she was being asked, but realizing it was literally not possible to be in the NICU while simultaneously caring for her son at home. She identified having to push through her own hesitations to ultimately ask for help. She stated, “I do have some difficulty asking for help, and with like wanting to just try to like do everything. So yeah, that was a hard thing for me.”

Abby reiterated the pressures of the Juggling Act and the subcategory of self-sacrifice. Self-Sacrifice represents how women attempted to ignore their own needs by choosing to put their infants first. Abby confirmed this subcategory in round-two interviews by sharing about how she overlooked her physical needs and also her mental health. She shared, “I was just trying to be at, you know, like a 100 places at once, and I just couldn't…” She continued on in her interview discussing the ways that she sacrificed her own mental health and well-being in order to take care of her daughters:

- I think I was so worried about taking care of everyone else’s [mental health]. I didn’t take care of mine (crying)...So for me, I felt like (trails off).. I was on antidepressants and stuff because I had suffered with postpartum depression, and then I had so much going on with them in the NICU. So, I was taking my medication, but I wasn’t getting good sleep. I wasn’t showering. I wasn’t eating. I wasn’t taking care of me to where I could be the best version of myself for them and my other kids. I was just, I was going on fumes. And I think that’s what moms do.

The subcategory Nonlinear Medical Progress was confirmed in round-two interviews as another experience to juggle. Women spoke again about the emotional and mental challenges they faced due to their infants’ fluctuations in medical progress. Ellie articulated her surprise surrounding the ways that her understanding and expectations of progress varied from reality. She identified feeling scared and experiencing uncertainty about the possibility of medical
complications after realizing that breathing challenges were not the only barrier her son faced. As Ellie shared, it became apparent that her emotional and mental energy throughout this part of her experience was focused on her infant’s health, rather than on her own internal experiences of the ups and downs of his health. Again, an aspect of The Juggling Act is that it served as a way for participants to stay externally focused rather than focused on their own internal experiences. At the end of her statement you can begin to hear her worry for her son’s health emerge, although she doesn’t elaborate or stay with the emotion of her experience. She stated,

Yeah. And it just had surprised me, because I guess I naively assumed that for NICU babies, ‘Oh, it's always breathing issues' and you know [Tom] was only on CPAP for like 12 hours. So, it just took me by surprise. When he was weaned off the CPAP, and that was successful, I kind of thought, ‘Oh okay, we're good. We're just going to work on eating and going home.’ And that wasn't the case. So I think that just kind of threw me for a loop…. Like, ‘Oh, my gosh, if it's not about just breathing, then what? It could be about all of these things. What else are they not considering?’

Abby identified in second-round interviews the frustration she experienced receiving vague information about how and when her daughters would be discharged to home. This lack of clarity lead to increased difficulty for her as she navigated the Nonlinear Medical Progress of her infants. She shared, they would say, ‘Well, we can't tell you a date. But yeah, they're doing great. They just need to put on a little bit more weight.’ And I’m like, ‘okay, then, that should be easy,’ you know, but no, it was like the longest process of my life.” Here, Abby briefly mentions her own struggle, but the emphasis remains on the wellness of her daughters and the mental challenges she faced of their nonlinear medical process. She highlights how the changing and uncertainty of her daughters’ health in order to get home, adds a mental challenge that she has to manage.

Round-two interviews further defined the aspects of The Juggling Act that women faced. Participants reiterated the logistical and mental/emotional tasks they were faced with. They also
reinforced how The Juggling Act allowed them to focus their attention outward. As women described this external perspective, women began to narrate how they began to reflect on their internal emotional experiences when being faced with the possibility of death around them. They described feeling the ‘heaviness’ of the NICU. The **Pervasiveness of Death**, is the aspect of women’s process in the NICU where they began to experience their internal emotions, rather than staying focused externally and on *doing* and managing the experiences around them.

**The Pervasiveness of Death**

The pervasiveness of Death emerged after round-two interviews as its own category. This theme is about the challenges that participants faced as they navigated the reality of death around them and the nature of the NICU. Despite the positive actions and intentions of the NICU to save babies lives, the connotations associated with the NICU include the obvious reality of sick babies and the possibility of dying babies. Within this theme, women described their experiences of avoiding the thoughts of their baby dying and simultaneously grappling with the idea.

Women described *Both/And* experiences in which they would identify on one hand wrestling with the fear of their child becoming sick enough to die, knowing that death was a possible option, while simultaneously not allowing themselves to traverse that emotional space. They describe compartmentalizing the severity of the trauma they experienced during their NICU stay. Some participants shared about their compartmentalization as a coping strategy in order to continue showing up for their children in the NICU. Women described their sense of knowing they needed to show up and be present for their infants as more pressing and prominent than grappling with or addressing their own fears. Subcategories that emerged in the **Pervasiveness of Death** during second-round interviews include *Fear of the Unknown* in which
participants identified being faced with the uncertainty about their infant’s life and the coinciding possibility of death. *Preparing for the Worst* is one way women took in information regarding the sick infants around them and subsequently using that data as a comparison or possible marker for the wellness or future struggles of their own infant. A final subcategory that emerged within this category is *Self-preservation via compartmentalization*. In this subcategory women described the ways that they worked to compartmentalize their worry and fear to protect and self-preserve their functioning to stay present for their infants.

Brooke summed up the *Pervasiveness of Death* when she shared about her desperation and simultaneously shutting down of her struggle with the thoughts of her daughter dying.

I had to really just not allow myself to go there [to death], because when I did it was... it was desperate. It was like a desperate, all encompassing, feeling that I couldn't get out of. And having experienced that like a couple of times while we were in the NICU, I just needed to not let myself go there.

She continued,

And so there were several times where I would be...because I love Jesus. My relationship with God is very, very important to me. But there were several times where I would be cussing out God in my car, because it was like, ‘How are you gonna let this happen? How are you gonna let this happen to us?’ And there were several times that I did that in that car, you know, in that space. Especially when she was septic. When we found out that she was septic, and we had to do the gram stain from her spinal cord. I was... we got off the phone with our neonatologist that night because it showed up pretty quickly and I looked at my husband, and I was like ‘if it's in her spinal cord, we're screwed. She's gonna be dead. We are screwed.’”

**Fear of the Unknown**

*Fear of the unknown* is about women’s experiences of confronting the possible outcomes their infant could face. Women described how the nature of the NICU implies the presence of very sick babies and even the possibility of death. Participants described their fear and desperation as they journeyed through the NICU with their infants, uncertain of whether their children would be okay.
Abby confirmed this subcategory clearly with the statement,

I think it's just the unknown... I think a lot of people struggle with that, not knowing if your baby is going to have to be in the NICU. If you do, not knowing what's going to happen to them when they're in the NICU, what they'll need done, how long they'll be there.

Abby also described her experience of immediate fear upon having her infants taken to NICU and needing high levels of support. She described her experience of hearing this news and automatically having concern about the possibility of her daughters dying. She articulated,

So all I hear is, ‘Oh, yeah, they got taken to the NICU. They have everybody helping them both lot.’ And then that's it. So, just the thought of your own babies could possibly be dying like that was extremely emotional.

Later in her second-interview, Abby restated how her learning about the need for breathing machines left her with concerns about her daughters’ ability to survive and the deep fear she experienced. She stated,

So yeah, right after they were born and they were just taken away from me. Like I didn't know what was going to happen. I didn't know if they were going to make it, you know (crying)…They said, oh, they need to be on a breathing machine and c-pap and all this stuff, and it's like to me like that means they're not breathing. So yeah, it was extremely scary and nerve racking.

Ellie shared about how her fear of the unknown began to lead her into a spiral of questioning about what else could go wrong and how close her son was to death. She shared, “So, every little lab value, ‘Okay, his platelets dropped a little. Does he have a brain bleed?’ There is just always that overarching fear of ‘What is it?’ You know, ‘How close are we?'”

A few of the women described not necessarily considering the death of their own infants, but still wrestled with a fear of what the possible outcomes and consequences the future held in an environment where death was a very real possibility for others. Lindsay shared,

I was not really thinking about that (death) sooo much in relation to my son because, I mean I was definitely like worried for him. And I was, you know, worried a lot about things, like more just like effects on his overall health or development, but I wasn't as
much concerned about the possibility of him dying. I mean, you know that there's... it's [death] not all that uncommon... I mean, it's the nature of that place [NICU] and what's going on there.

Jessie discussed feeling less concerned about her own child's death, and it not being a part of her reality. She shared,

Yeah. (pause) umm... I don't think I necessarily thought about him dying. I don't even think I conceptualized that. I just don't even think it was a thought for me, because we weren't in like (trails off) ... I mean, I think it was after the first day he came off oxygen. So, by the time I was catching up to what was actually happening he was coming off of everything [medical interventions], and I was just becoming a mom. So, I don't think for myself, I don't think death was even a concept...

Preparing for the Worst

Participants described preparing for the worst by taking in data about the infants around them. Here, women described being stuck in the Pervasiveness of Death, knowing that babies around them were sick and dying and taking that information in, in order to determine their own infant’s proximity to death. They described making comparisons. Often finding internal relief when placing their infant next to information regarding the other infants around them, or on occasion, finding an increase in their distress and fear for their own infant’s wellbeing.

Andrea confirmed how being surrounded by sick and dying babies allowed for an opportunity for constant comparison. Andrea described seeing babies that were sicker than her own, and realizing the intensity that other mothers were experiencing and the possibility that she could be facing with her son.

When we were in NICU, you know you have your little video, that’ll show your baby's vitals. But then a lot of times, I think they do it for purposes, if you know the nurse who has a few babies assigned to them for that day, you know they have all their vitals also on the screen. So, when you're there and you're doing your baby's care time, and you can see what's going on with the other babies. I feel like when you're sitting there, and you see, like another baby's saturation levels are dropping, or their alarms are going off, or the blinking, and it's, the alarms are sounding, I think I feel like your heart stops because you're like, ‘Oh, my gosh!’ You know, if that was something, if that happened with my
baby I couldn't even imagine, as a parent. And yeah, I feel like that piece is kind of, it gives you even more anxiety.

She continued on,

I think just being around (pause) I mean (pause) death...And just sick babies, too. But you know, when you're in a room with 3 other babies, and you can literally hear the conversations happening openly around you. Or even, I think too, we were in one of the rooms further down the hall. So, as you're leaving you are passing several babies rooms as you're walking out and walking in. I remember my husband and I, we were visiting one night, and there was a new baby. It was in one of the first rooms on the righthand side, and I just remember the baby was soooo tiny. So, so tiny. It [baby] was in the full incubator, and had, little, eye-goggle things on, and I mean, just so much more than my son had, and I was like, ‘I...I could never imagine.’

Andrea later continued describing how her experience of intaking information, and an absence of data regarding the babies she was surrounded by. This absence of data created deep internal distress as she realized the possibility of infants around her dying. She articulated the emotional struggle she endured:

Yeah and when you no longer see a baby's name on the shared monitor, or that baby's room is (pause), empty now. And their name, you know they have all the baby's names on their doors, and I remember during the time, it was St. Patrick's Day, so my son, every single baby, had like a little St. Patrick's Day decoration with their name on it and their little handprint. I mean the NICU nurses are so freaking amazing. Anyways, but you see all those little things, and then it's like- oh, everything's been peeled off the door, and you're like, ‘Well, did they? Did they make it? Did they get discharged because they passed their car seat test, and they are at home with their mom and dad? Or did they not make it?’ And you're just like, 'Oh...(frowning).'

Abby described her experience being in open bay and watching infants leave the NICU.

The data intake she described, was absent of enough data for her to actually make sense of it.

This led to Abby being faced with deep internal distress for other moms, as well as magnified worry for her own daughters’ wellness. She reported,

We were in like a huge room with little, you know the beds everywhere and I would go in several times a day. There would be babies there. Then, when I would come back, there wouldn't be. I didn't know what happened to them. I didn't know like, ‘Oh, did they graduate and get to come out of the NICU? Or did they die? Did something happen to them?’ And one baby did end up going into cardiac arrest when I was in there, and they
had to ask me to leave. So that (silent and tearing up) … It is [tragic] (crying) because, it's like as a mom you don't want that for anyone. And then you know, it just makes you worry like 10 times more about your own children.

Jessie also described her awareness of sick babies around her and how this led to considering the presence of death around her. She shared,

We did notice like there were a lot of other babies that were in their incubator, and under the light like 24/7. And so just… and not, you know you can't really ask the nurses about what's happening. But you're just really concerned about them. And, because then they don't have family with them. You notice, like people aren't coming in and out. So yeah, I think that's the only time that I think that was thought of it [death].

Jessie then continued sharing that even when she was not considering death, she was taking in information about other infants. This information then informed her fear about the possibilities of the process. She shared, “But I did get to see, that there was one baby. There was one baby that had been in there for like several months. So, I think just seeing like how, how long that process could be. That was hard, not knowing.” Similar to Jessie, Lindsay shared about how the knowledge of death being present in the NICU influenced her emotionally. She also described using comparison to measure her son’s proximity to death and to simultaneously find relief in their situation.

I mean, I feel like that knowledge is definitely there, and it colors your feelings…. In a sense that you definitely feel like, in some sense, relief. Relief that you're kind of where you're at, you know, versus others. So, it's just like a really sobering kind of thing… Because you just realized how close you are to all of that [death]. And yeah, I mean it's present. And you're aware of it.

Abby articulated her experience of moving from fear of death for her own infants to the presence and possibility of babies dying around her and the different stress she experienced internally because of situations she witnessed.

It was different, but I think it was a different level of concern or different level of stress, because I was there every day, all day long. Not all other parents could do that. So, it's like I could hear other babies crying, or I could see nurses, or several nurses going into one room at a time. And then you're wondering like, ‘Oh, my gosh! Is that baby okay?
Where's that baby's family? Where's that baby's mom? She probably has no idea what's going on right now, and she's not here.’ So, it, I think it was like a whole other, you know, like completely different aspect, to have to navigate through.

**Self-preservation via Compartmentalization**

This subcategory of the **Pervasiveness of Death** captures how women used compartmentalization from the possibility of death of their infants, and those around them, to remain present and self-protect from the intensity of the trauma and emotional distress they faced being in the NICU. Women described not being able to even grapple with, or address their feelings and thoughts about their infant’s possible mortality. Women also described their experience of moving into private rooms as a mechanism of compartmentalization. Women articulated how they self-preserved by compartmentalizing in order to be present with their infants and to remain in a functional state.

Nearly all of the women described using their single rooms as a mechanism for compartmentalization and finding peace in being separated, despite the isolation and loneliness they endured, in part, because of the single room.

Andrea described this as,

> I feel like you are kind of in your own little bubble. Your little safety bubble being in your own private room. And so yeah, you're hearing the alarms go off, and of course, the realization of, babies are potentially, could be, dying around you. But I feel like you're just in your room with your baby the whole time. So, I don't think I was experiencing it as much when I was rooming alone.

Abby also described finding solace in her daughters move to a private room. She described refocusing her energy solely onto her daughter’s wellness rather than continuing to manage her energy and emotional intake around the health of the other babies around her.

> So yeah, that, that was extremely hard. It’s [death] something that I feel like I didn't really think too much of after they got moved up to their own room. After that I was like, ‘Oh, they're in the clear. They're, doing good. They've graduated to a lower level NICU area.’ So, for me, my main focus was just on them, because I wasn't in a room full of
other babies and other moms. We had our own room. So, it's like, I don't think I ever really thought about it again until now. But, I remember that feeling, and it was an awful feeling.

Similarly, Ellie shared, “And then, once we were up in our own room. It just kind of was a non-issue, because I never saw any other alarms or heard any other alarms, so I didn't really think about it.” Jessie expressed a similar convenience to have a natural separation from others once placed in their own room.

You know, it was COVID, so there was a lot of precautions around like interactions, and we really just stuck to inside our like little room. Even leaving was minimal just because of that, and because they were also very strict on kind of that process. So, I didn't really get to interact with a lot of other parents.

She continued on, “Yeah, I guess it was kind of nice, because we didn't really get too much interaction, and I don't know how…. And, I don't know how much his dad and I really would have interacted with others just because we're not really that outgoing.”

Brooke’s experience with compartmentalization was very rich and deep. Brooke’s encounters with her infant’s risk of death were multiple and serious. Brooke identified that despite her daughter facing many challenges to her life, she avoided the intensity of the experiences she, herself, was navigating:

Like that's just normal [to prepare]. Our brain is trying to prepare that to protect us. It was really challenging. I mean, I think deep down, I never really let myself get to the point that, ‘she's gonna die.’ I think I always knew it was a possibility, right? You are in NICU. You know that things can happen. Especially, I mean, she was born at 27 weeks. She was 2lbs 2 ounces. So tiny. We experienced all the things that you can experience in the NICU, with the exception of brain bleeds. That was the only thing that we avoided. But we literally had everything happen and, it was just... It was one of those things that I never let myself grapple with.

Brooke continued on explaining her reasoning for compartmentalizing and not allowing herself to truly grapple with the possibility of her baby dying. She shared,

I knew that in order for her to survive, I had to be the strongest I could be for her. Because I was there constantly, and I knew she needed, even if her eyes weren't open,
even if she had like pain meds in her body because she was septic. I knew that she knew I was present. I just knew that she knew I was there, and so I had to really just not allow myself to go there, because when I did it was it was desperate.

She described the compartmentalization as,

While I have big feelings, and I’m super passionate, and I'm willing to express those feelings, when it gets bad enough I compartmentalize right? So, I am like, ‘Okay. This [death] can happen. I have to stonewall. Protect myself.’ So I can acknowledge that it happens, I think that's why I have like such intense posttraumatic feelings. Because I've had to compartmentalize in those instances.

Brooke also shared about how she redirected her focus towards being present for her daughter rather than grappling with her own fears of her losing her daughter.

I think, even more so than focusing on the hope, I needed to focus on how best to support my daughter in that time. ‘How can I support her? She's miserable right now. I can put my hands on her belly so she can feel me. I can sing to her. She can hear my voice. I can read to her, I can pray over her. That's how I can support her.’ So I compartmentalized all these crazy feelings of real possibilities of losing her. But my job at that moment was to support her.

Deep Dark Battle

The Deep Dark Battle highlights the internal struggles women negotiate while having an infant in the NICU. Second-round interviews confirmed this theme and the many ways this internal downward spiral manifested. During second-round interviews participants offered data confirming subcategories of the Deep Dark Battle. The lonely subcategory added multiple experiences of emotional isolation. Good Mom/Bad Mom Dichotomy was another subcategory that women confirmed with second round interviews. Here, participants reiterated messaging they told themselves and messages surrounding them about what a “good mom” does, and how that influenced their experiences during their time in the NICU. The subcategories of Guilt, Failure and Shame also reappeared in second round interviews confirming these experiences for women.
Second-round interviews revealed that participants’ entry into the Deep Dark Battle varied. Varying degrees of depth of these internal struggles also differed, as did the magnitude of women’s internal struggles. For example, when Jessie entered the NICU, she was facing multiple and significant challenges in other aspects of her life. Her experience and time in the NICU was not the most significant struggle in her life. Given this, the depth and report of her experience in the NICU looks different than other participants’ Deep Dark Battle, and yet also provided clarity for her responsibility to protect and prioritize her son. Although Jessie described experiencing some of the aspects of the Deep Dark Battle, such as body failure and guilt, she reported never being deeply worried for her son’s wellbeing or life. She reported very little about personal emotional distress, shame or despair in the NICU. Rather, she discussed how the NICU magnified her strength and commitment to her son’s wellness both in and out of the NICU. She shared,

Well, you know this experience it was, although it was very traumatic in the sense of just like how everything played out. I think it just showed me right away what being a mom is. And that I’m more than capable of doing, you know, whatever it is. When it comes to my son, especially in regards to like him being as small as he was, and coming as early um, and knowing that I’m capable of taking care of things, regardless of circumstances.

Interviewer: Yeah, like almost the NICU experience highlighted your ability to be (cutoff)…

Jessie: Yeah and the strength that I needed to like, even like now, I think it's set me up so much for like how I can put us first, and then also, but also take care of everything else. Secondary. Like his well-being and making sure he's, like all his needs are met as number one and priority, and then it's like, but then also mine. And then you know everything else will follow.

Jessie also articulated the NICU as being a time of peace that she later didn’t experience. She stated,

It was…So, where things are at now, the two weeks that we had in the NICU, I think, was probably the most peaceful part. We had no outsiders coming in. We had nobody telling us how we wanted to raise our baby, or like… We just got those two weeks of just being parents and being a family. With the help and support of people that you know, were meant to be there to support us.
Other women experienced the Deep Dark Battle saturated with personal despair, shame and guilt. Ellie described the intense guilt she navigated, and continues to navigate even 18 months post-discharge. She shared about her feelings of desperation during the NICU stay, describing the NICU as a purgatory experience. This depth of the Deep Dark Battle is significantly differing from the depth that Jessie described in her experiences with the Deep Dark Battle.

The subcategory of *Lonely* was touched on briefly as part of The Deep Dark Battle, once again. Andrea reiterated in second-round interviews being alone both emotionally and physically. She stated, “Yeah, I mean, I think my biggest thing. And I think I told you in our first interview, like I felt so secluded and kind of like… You know you feel alone. Like not many people really experience what you experience.”

Second-round interviews also continued to highlight the messages that women hold in the rigid *Good Mom/Bad Mom Dichotomy*. In second-round interviews, specific messaging that good moms do not need to ask for help, bad moms are selfish when they put themselves first, and good moms protect their babies. Lindsay shared needing extra support, and the continued narrative she held about being a burden if asking for support. She shared, “I mean, I know that even though you know that other people want to help, it's hard still to ask them. You don't want to feel like a burden, but I think that it's important to ask for help if you need it.”

Brooke discussed her thinking and internal messaging that “good moms” have instincts to protect their children. For her, this message emerged in keeping her emotional process separate and hidden from her oldest son so that he would be protected from what he was not able to understand.

It was like a weight, you know, like it was like almost like I had to put on like an armor going into the hospital, and then, like release, try to release the armor, leaving the
hospital because I have a two-year-old at home. So, I really wanted to maintain some normalcy for him because he doesn't understand what's going on. He knows that his baby sister, whom he's never met, is no longer in mommy's tummy and that she's really sick in the hospital. He can understand she's sick. She's not in my belly. But he can't understand what that feeling is doing to his parents. And so that was another, like I need to compartmentalize here, so I can be present for him, you know? I think that's just like such a natural thing for Moms especially, to do, right? To be like 'I don't want to project what I'm going through on to my kids who have no control over that, when they're tiny little brains are trying to form, and they're trying to figure out those relationships,' you know. So, you just get through it.

Abby shared about her experiences of her own decline in mental health due to messaging that taking care of yourself is selfish. Despite holding this message, she reflected that in retrospect it would have served both she and her daughters to have considered her own wellness first. She articulated:

But yeah, I think, I think this is the time where it's okay to be selfish. It's the (crying), it's okay to, you know, make sure that you are okay. First. And as a mom like we don't ever tell ourselves that…and it's sad that we think of it that way (taking care of self as selfish), because as moms, we're not used to putting ourselves first. I definitely think that's the most important thing that I feel. If I would have done that, I would have been so much less emotional. And so much more (thinking) like I would have responded better to the things going on around me I would have responded better to their health. To any of their updates and stuff like that. I think it would have just made me be able to take this, the situation, a lot easier than what it had to be. I feel like I kind of made it harder on myself.

She continued on identifying her definition of a mom and reflected “You know to me the definition of a mom is like always putting your children's needs first. And always making sure they're okay, and they can't be okay if you're not okay.”

Participants also continued to discuss their experiences with Guilt as a part of the internal battle they faced while having their infant in the NICU. In second-round interviews new aspects of feeling guilty emerged. Women described feeling guilt when suffering less than other women in the NICU, and encountering guilt when their own infant’s health compared positively to infants around them. Ellie described an encounter at work, in which she experienced some PTSD symptoms and a reminder of her own severe guilt.
The other night at work… It was another nurse who was taking care of a NICU mama, who had twins at 25 weeks, and they ended up, not making it. She had to go over and say goodbye to them and the neo that was like on call was like our favorite [Dr. X]. I will always have a place in my heart for her. She came over to get the nurse to tell her. I could tell she had been crying, and I'm always just touched by how it never gets old to them, you know, like they're always crying when they come over for that [to share news]. The nurse was telling me while, she was over in the NICU with the mom, and you know I had to work on getting her anxiety medication, but she was telling me that the patient just was like: what could I have done differently? Like, what did I do wrong? Just all those like, you know, the guilt. And she said, almost verbatim, like it was a memory that I didn't remember until she said it. that [Dr. X], had kind of said the same things to me. It was like, you know. She's like you went to all your appointments. You didn't use drugs like just very basic things, but just kind of talking you off the ledge in that moment, you know (crying) And then, when she said that it was. It was like it took me right back to [Dr. X], telling me those things when I was, you know, having my day where I had a meltdown and was feeling guilty. And, And yeah, it was just a reminder of how, I mean, obviously, the outcomes were very different. But that guilt is just…it’s intense.

Brooke described feeling guilt when experiencing happiness preparing to discharge while also watching another mother’s infant pass away. She articulated, “It's just…the next day, I remember feeling, ‘how can I be happy?’ It’s almost like a survivor’s guilt. Like, ‘How can I let myself be happy when they're going through so much pain?’

The subcategory of Failure was confirmed when Jessie described her sense of her body failure and experiences of the failed vessel. Jessie reflected on the care she wished she gave herself throughout her pregnancy. Describing

I think the only thing that you know has come up through this process was like having, I think we talked a little bit about the shame of not being able to like carry him, in like the right way. As a native mom trying to embody, you know, like overall health and well-being, I think it was just really important for me to limit my stress and my environment. The stress in my environment and everything. Taking care of my body, by like eating right and exercising. Some of those things like I just wasn’t attending to that like led to that. And so, I think you know, when thinking about, maybe not necessarily for NICU Moms, but just mom's, you know, new moms or pregnant moms in general, is just listening to the doctors and tending to yourself, and really just so that it doesn't lead to these high-risk situations.
Abby reiterated the intense Helplessness she experienced. She not only felt helplessness for her own experience, but also for the other women around her that she observed suffering. She shared,

But yeah, it it was... Yeah, it's hard to see other moms going through something and that you can't really support them as like a mother and a woman... Yeah, that was... (pause)... It was awful. And it's awful feeling. Feeling helpless for not only yourself and your situation, but for other people.

Andrea also described feelings of helplessness about others suffering as well:

Just feeling so bad for the parents, because, you know, you see this Mom who's being wheeled in. And I mean, I think she must have just had the baby. The Dad is standing in there, just doesn't know what to do. Then the mom is getting wheeled in, you know, after the fact, in her little wheelchair, and you're just like... Ugh. It's almost an indescribable feeling. You just feel so awful.

In second-round interviews, Shame was confirmed as a subcategory of the Deep Dark Battle. Ellie shared her brief sense of relief after delivery, followed by an intense experience with shame about her decision to have a C-section, and her perceived responsibility for her son’s health complications. She shared,

‘Oh, maybe I got this wrong. Maybe he's not as safe out here, and maybe he should be inside, and maybe I should have...’ You know, ‘What could I have done different?’ And that whole loop. So I'd say for me it was, it [shame] was delayed. It was like a honeymoon period of a couple of days where I just really felt like, you know it was fine. And then yeah, and then....

Despair and Hopelessness is another subcategory confirmed within the theme of the Deep Dark Battle. One aspect of this desperation was confirmed in the property of Desperate to get home. Abby spoke again about her desperation to take her infants home.

And then... I was so unrealistic too. I kept thinking, oh, they just need to gain weight. ‘So, do you think they'll be home by Christmas?’ ‘Do you think they'll be home by this date?’ And I wanted a date. I wanted to know a date that I could take my babies home.

Brooke also confirmed this subcategory of the Deep Dark Battle when she shared,
But as soon as she [another NICU infant] died, it was like, ‘You cannot get me out of here fast enough. I will do whatever we have to do to get her out.’…. It was one of those things, ‘I can't get out of here fast enough I will do anything to get out of here.’

Another property of the subcategory of *Despair and Hopelessness*, is *Personal Despair*. Second-round interviews offered confirmation of this property. Abby shared her experience with despair. She stated,

I have been through such hard things like I've been through, like you know, death of loved ones. I've been through rape and molestation, and I've been through, you know, being held hostage even, and stuff, and it's like none of that compared to this, none of it. Because it's like your child, and so you know, you can put yourself through anything. and you could be strong and get past it. But when you involve your child in it, you know it's a completely different feeling.

**The Deep Dark Battle** was not a primary focus during round-two interviews but did continue to saturate with new data and references to this theme. Women again referenced their inward downward spirals. They described experiences they faced of navigating their emotional experiences of being emotionally lonely, feelings of guilt, shame, failure, and despair and helplessness.

**Escaping the Spiral**

**Escaping the Spiral** is how women worked to find support for themselves while in the midst of enduring their experience of having an infant in the NICU. This theme focuses on how participants implemented coping skills and supports around to manage their many responsibilities and their emotional processes. Second-round interviews confirmed that having *Family* to help was important. They also confirmed *Social and Online* support as a coping skill. Finally, women confirmed how having *Attuned Care* was supportive to their upward spiral. Lindsay reiterated the importance of having support. She shared that despite a lack of desire to ask for help, a confidence in knowing that people were wanting to offer logistical support.
I mean, (long pause) I guess, you know I needed it (help). So, I had to ask. I mean, I'm really lucky, because I didn't have to beg either. You know, I have these people that I just needed to say what I needed. They (friends and family), they just needed to be told like what I needed from them, you know…And I definitely had like feelings of gratitude and relief, you know, to have that help at the time.

Andrea confirmed how *Social and Online support* acted as a resource for women working to escape from their downward spiral. She shared that connections made through this support strategy were encouraging. Despite women desiring in person for connection and understanding, that need went unmet and they sought out supports on social media. Andrea described having an old cheerleading friend reach out to her on social media to offer encouragement.

I think one of the nicest things that I had when my son was in the NICU was one of the girls I cheered with my entire, you know, cheer career basically, she's a NICU nurse. She was like, ‘Your baby is where they need to be. And I can't tell you how amazing NICU nurses are, and how much we love and care about these kids. They are the best, these babies. We're so protective over these babies, you don't understand.’ She's like, ‘Even more than you know.’ She's like, ‘These babies are like our little…’ So, I think, just having people reaching out when I was in that situation was super helpful.

Andrea also confirmed experiences with *Attuned Care* for her child in second-round interviews. She shared again about the way that the nurses were deeply caring for her son. She described this care as a secondary gain for her own wellness.

And you know the NICU nurses are Angels. On. Earth. And they love your baby. I mean the doctors, everyone, respiratory therapists, everyone who's involved. I feel like their goal is to make sure that your baby gets healthy and can get discharged, and I feel like they're, they're always on your side like rooting for you and for your baby. And I feel like sometimes it, it doesn't feel that way. But I feel like, you know, it is.

In round two women reiterated the *Trust in the Medical Support* they experienced for their children. Ellie shared again about the relief she experienced shortly after the birth of her son, reinforcing her trust that her son was in good care. She stated,

I think I shared before, but, I mostly just felt like relief when he was out [after delivery]. Like I genuinely felt like he was gonna be safer in the NICU, and that, the nurses and
doctors could take care of him better than my body could, and that was kind of my first…
I just felt so relieved.

Jessie also mentioned in round-two how the trust in the medical staff, their skill level, and their positive engagement with she and her partner was supportive and attuned to her, creating positivity during her NICU experience. She reported,

I think I really appreciated the nursing staff and just how like gentle they were, and how like hands on they were in like teaching how to be a parent. But then also how to take care of a really small infant that had all of these tubes. So, they were really patient and really kind with their approach. I think that helped the process, having a care team for both of us. That was like supportive of us, and always commenting and reflecting on how much [time] we’ve spent with him, and the work that we were putting in. I think that really helped us and motivated us to continue to keep doing what we are doing.

**Post Discharge: Integrating the Deep Dark Battle**

This theme is defined by the experiences that NICU mothers faced after their infants were discharged from the NICU. This theme developed radically in second-round interviews.

Second-round interviews revealed that participants spiraled to varying degrees into the Deep Dark Battle. The differences among the depths that each woman had to journey inward informed, in many ways, the extent of how much integration needed to be done in the post-discharge journey. Second-round interviews provided a glimpse of these differences by the amount of disclosure women offered when asked about meaning-making, where women’s depth of the experience of integration also varies. Second-round interviews added clarity to this superordinate theme in significant ways. After first-round interviews women’s experience of post-discharge from the NICU included brief descriptions of continued anxiety, continued medical complications for their infants and reflections on their desire for support and understanding. Second-round interviews asked more specifically about post-discharge experiences and how they have made meaning of their NICU experiences. Subcategories that emerged from second-round interviews are **Post-Discharge Trauma** with properties of fear and
anxiety, re-experiencing, hypervigilance, and ongoing experiences with death. Other subcategories of this theme include: *Continuation of Guilt, Continued Medical Complications, Reflections of Pride, Longing for Understanding and Connection, Finding Meaning and Messages to NICU Moms* with properties of *Your Experience is Valid, Ask for Help, and Take Care of Yourself.*

Women described the post-discharge process as a continuation of the NICU journey, without the medical support for their infant. Although the immediacy of the NICU was no longer present, women discussed the continuation of guilt, anxiety, distress and fear due to their experiences in the NICU. After discharge women reported experiencing aspects of the Deep Dark Battle. The Deep Dark Battle occurred *during* their NICU stay, and their experiences of this inward spiral had not been addressed, communicated, integrated, nor made meaning from during their time in the NICU. Although they were no longer in the throes of their NICU experiences, women described a growing awareness of their babies doing well and getting healthy while they themselves began realizing the magnitude of their own experiences with the Deep Dark Battle. Post-discharge, women began to comprehend the amount of emotional distress they personally experienced. Women highlighted the abrupt ending of medical support for their infants, and negotiating experiences ending the medical interventions their infant relied on in the NICU. They discussed the intense fear this discontinuation of care triggered for them. Although women described the intensity and negative emotions they experienced watching their infants be hooked up to breathing machines, IV’s, alarms, monitors, and other supports, it became apparent in the data that participants also found comfort in these devices. The medical interventions brought a sense of comfort and knowing about how their infants were doing.
As participants shared, they began describing sifting through Post-discharge Trauma. Participants shared having physical responses to specific triggers, having their senses inundated with memories, and hypervigilance about their infant’s health. In the post-discharge experience anxiety and fear were prominent as the absence of medical information and devices created a lack of data women depended on to monitor infant health. Women also expressed fear and anxiety about the continued wellbeing of their infants, and the continued fear about the possibility of their children becoming sick again. Women also described a continuation of their experiences with death and the emotional tax of this burden.

A new subcategory of the post-discharge experience is the Continuation of Guilt. Although their infants were healthy and home, several participants described their continued navigation of guilt. Additional categories of the Post-Discharge Experience included navigation of their infants Continued Medical Complications while also shifting their focus to Reflections of Pride in their infants. In second-round interviews women confirmed their desire for Longing for Understanding and Connection post-discharge. Participants further described their process of integration of their experiences in the Deep Dark Battle by Finding Meaning and creating a new story about their NICU journeys. Women used advocacy as a way to make meaning of their experiences and offer care to others. Finally, women experienced further integration by reflecting on their own desires during their NICU stay and offering pieces of advice in the subcategory Messages to Future NICU Moms.

Post-Discharge Trauma

Participants described navigating traumatic emotional experiences. Women identified having intense fear and anxiety which informed many of their decisions, feeling, and thinking patterns. Several of the participants described re-experiencing aspects of their trauma. Finally,
women outlined their own hypervigilance caring for their infants, and managing concerns about their safety and risk. They shared the ways that their fear from their NICU stay contributes to a loss of joy and a chronic anxiety about their infant’s wellbeing. This experience of post-NICU trauma creates continued barriers to the women’s wellness. Ellie described her experience as,

“It’s just interesting how it's [trauma of NICU] just, it's still just right under the surface, you know (crying). And it's like you have to go through those things that, that are just gonna bring that back up. But you know he’s been sick since then, and we didn’t need the nebulizer.

She continued on, describing how experiences from NICU are impactful and profound, leaving her often feeling like she is just surviving. She shared, “It's loaded right? It's not like nothing…And not wanting to just always live from that survival place.”

**Fear and Anxiety**

In second-round interviews all of the women discussed their fear and anxiety for their infants post-discharge. They described challenges with meeting their own basic needs such as sleep, due to chronic worry and fear.

Jessie shared that her post-discharge anxiety was the time that she actually did worry about the possibility of death for her son. She expressed,

I think it was more so of like, you know, ensuring when we left (emphasized) the hospital. I think that's the only time [I considered possibility of death]. Maybe, was him having SIDS or something, because he was so tiny. And so I was super cautious. I had like one of those owlet monitors. And, yeah, just very aware, I think, after the fact versus like being in the NICU.

Jessie described how she found comfort from her worry by using her own home monitors.

Well, and then you have like a 4-pound baby that… and I co-slept. I didn't, I mean, I used a bassinet. But he slept so much better next to me, and so that was really new for me. So, I was really thankful we had that monitor just to be able to see.

Brooke described the intense anxiety she felt as she learned about not having monitors after discharge from the hospital. “You mean, I'm not gonna have a pulse ox at home? like I'm not
gonna have these monitors? I won't be able to see what her heart rate is? And you're not going to give me like an alarm when she stops breathing? I just have to trust that she's ready for this?"

Similarly, Andrea described in detail, how her NICU trauma has impacted her experience of her second pregnancy. She identified knowing that part of her experience comes from trauma and fear, and being unable to disconnect from NICU trauma to experience the joy that she hoped to have during pregnancy.

Well, I feel like mainly I've been just thinking in terms of like everything that happened within the NICU and how it impacted me. I have noticed, I think, in my first trimester I really didn't think much of it, but I think now like going into second trimester, and like getting further along, my anatomy scan is next week, and that's kind of when I found out that I had the placenta issues, and I feel like it was like bad news, after bad news, after bad news. Leading up to delivering at 36 weeks, and I feel like I've been having a lot more anxiety this time. Kind of like leading up to that [anatomy scan]. Is it? It must just be like kind of PTSD. I'm like, 'Is something going to be wrong?' I know that my placenta is in a better spot this time. But I'm like 'Is something else going to be wrong? or?' So, I've been having some pretty bad anxiety over that.

Andrea explained her deep concern about her second pregnancy becoming a high-risk pregnancy after her NICU experience. She shared about her intense feelings of anxiety, fearing a repeat stay in the NICU.

I talked to my OB about it. I was like, 'Oh, I'm just starting to kind of get nervous, and it was kind of this, is like around the time, you know, when I got bad news. And I need...' And I mean it was, I, obviously it (high-risk pregnancy) wasn't like the worst news I could receive. But I was like, 'You know I'm just like traumatized.' I don't think I could, I mean of course, like you don't have a choice if your baby comes early and they have to be in the NICU. But I was like, 'I just want to try to avoid it at all, all costs.' ... You know, I'm having a repeat C-section, and she's like, 'My goal is to just have you right at 39 weeks, and your baby is going to be fully, fully cooked and ready to go. And you know, you don't have any issues.' I'm like, 'Yeah, it's still like in the back of my mind.' ... Yeah, it's definitely...I'm like, I couldn't imagine (having second baby in NICU).

Ellie also described how her anxiety and fear has morphed post-discharge from the NICU. As her son no longer faces the same health challenges he did while in the NICU, her anxiety has morphed to other avenues. She stated, "Because you know, it [anxiety] always changes. It's like.
Then they're eating solids. You're worried about choking. And they're mobile. It just is ever evolving. And it's exhausting to think like, ‘Oh, I'm never not going to be afraid.’”

**Re-experiencing**

Participants described ways they reexperienced and relived memories of their time in the NICU. They described being triggered by sensory input and reliving traumatic events.

For Andrea, the NICU was so deeply a part of her experience, that even the mention of medical interventions activates sensory input in her body.

I was just talking about like the like, the little alarm box…and like the noise the alarm makes. Someone was talking about it on one of my NICU pages, and I was like, ‘Oh, my gosh!’ I could, I can hear that noise. Like it's like ingrained in my brain.

Brooke described her daughter’s readmission to the hospital for an RSV infection. When telling this story she identified her trauma response. She identified having a physical reaction and re-experiencing her fear of her daughter dying. She described her reaction learning that her daughter could need breathing support:

Oh, it was crazy! It was crazy how very real the visceral reaction I was having. Even just like being in the hospital. It was like, ‘Oh, God! Here we go,’ You know what I mean? And then, when it started getting bad, I was like… I think it's like NICU, you think intubation automatically means that they're gonna die. So I was like ‘She's, this is it. What? How am I going to live? How am I going to do this without my kid?’ It was wild. I mean, it was really kind of crazy.

**Hypervigilance**

_Hypervigilance_ is a property of the _Post-Discharge Trauma_ that women described as a part of and continuation of their NICU experiences. Once home, women described being hyperaware of their infants, always being on guard, and constantly scanning for potential risks and harm to their babies.

Ellie articulated this experience as a constant looming fear. She said “And now that like things are okay, but it's still kind of looming. You're still waiting for the other shoe to drop.”
She continued on, reporting the abrupt ending of care for her infant, while still having deep fear for her child. She articulated that although the medical intervention ended, the trauma and fear did not. She identified that her fear was placed into other avenues of worry.

Yeah, and I think that was kind of hard too [preparing for discharge]. It's hard, and like all of a sudden. Then they talk about discharge, and then you go home. And where does that go [fear for child]? Right? Because that's still, it's still here. So then it's turned into ‘Is he cold?’ I'm like checking his temperature all the time, just waiting for…Like ‘What's it going to be? Is he sick?’ And that was really hard too, to figure out what to do with, you know. . . And then I think it just kind of turned into some postpartum anxiety and depression. And, Yeah. Still navigating that 14 months later.

Brooke similarly described her hypervigilance for her daughter.

She had her feeding tube, right? So, she wasn't really waking up in the middle of the night, like most kiddos would, because she was on a continuous feed at night. It was still one of those things that was, I was still not sleeping in any capacity. I was constantly like ‘Is she breathing, is she?’ She had really bad reflux for like 3 months, especially with her feeding tube. And I would be like, ‘Is she going to throw up in the middle of the night? And I'm not going to be there to hear it? So, I would very literally sleep with my hand on her chest with her bassinet next to our bed.

Andrea also described hypervigilance around her son sleeping. She expressed taking action to help her soothe her worry, but still engaging in frequent checking and scanning her son’s safety during his sleep.

I noticed, I still do it to this day, when my son falls asleep on the baby monitor, I'm constantly checking the baby monitor. I always do it as I feel myself starting to fall asleep at night. I’ll turn the baby monitor on. I'm looking. ‘Okay, is he breathing? Is he okay?’ And you know he'll stir a little bit and I'm like, ‘Okay, yeah, he's fine.’ And then I feel… then I feel… I cannot fall asleep without doing that…. I'm like, ‘It's almost going on two years girl, like, is this ever just gonna go away?’

**Ongoing Experiences with Death**

Women identified in round-two interviews, a continued experience with death around them due to their NICU experience. While being thankful of being out of the NICU and their child living, women also were still face-to-face with the loss that the NICU presented and the
magnitude of what they had lived through. Women described coming across content that
reminded them of their experience that were wrought with deep emotions.

Lindsay shared a story about the profound impact that an article she read had on her. She
identified that had she not had to navigate the NICU with her son, this article would not have had
the intensity it held. She shared feeling surprised by her deep sorrow as she read the article.

Yeah, just a week or two ago I read some article and this woman who lost her baby in
the NICU. She tried to create meaning in some way. She created this group that gives
books to families whose babies are in the NICU because one of the only things that she
felt like she could really do with her daughter was read to her. She wanted to remember
those times. But you know, she lost her daughter. Reading that was like, I just was really,
really emotional about it. Reading that. I know that definitely, that's because I had...Have
had a baby that was in the NICU and reading that I was just… it was so hard.

Andrea also shared a story about coming across content on social media that caught her in a
deeply emotional experience. She shared,

It sounds bizarre, but TikTok, this new platform, where, like so many parents, can like,
share their stories and experiences. And you know you start kind of seeing more stories
of moms being like, ‘Yeah, my baby passed away in the NICU at (pause) you know, two
weeks old or something.’ And you're just like, ‘Oh, you know, just like the death piece of
it. I feel like really it necessarily hits you harder…’

Andrea also shared a story about her experience of learning about the death of a baby that had
been in the hospital with them during her son’s NICU stay. She discussed the intensity of
emotion she had to navigate since discharge.

I did not think that this would hit me as hard as it did. But, and I’m sure being postpartum
at the time probably did not help my situation, because I feel like you're also very
emotional and sort of all over the place. But, the baby, I think you and I had talked about
it, the baby that passed away, the little girl. Her mom and I are…we still talk to this day.
But, I think like her passing away in the NICU, you know, I think my son and I had just
come home. Maybe we had been home for a few weeks, and she passed away. I was like
distraught over it. My husband came home, he's like. ‘What is wrong?’ and I’ve been like
crying all day reading about the post.

Continuation of Guilt
Women discussed the ways they faced a continuation of guilt even post-discharge. Ellie discussed continuing to work through her personal guilt for feeling responsible to her son’s outcome. Other women described guilt over other mothers’ infants being unwell. Two participants expressed a sense of survivor’s guilt for women who experienced a death of their infants.

Ellie confirmed the lasting effect that guilt has had on her life since encountering it in the NICU. She shared about guilt interrupting even their future family plans, questioning decisions to have another child.

It’s just interesting how it follows you because you start to look ahead to like family planning. And, and that just kind of brings up all the old, ‘Is this is going to happen again?’ And so that's the guilt thing. Even if it kind of waxes and wanes. But that definitely brings it more to the forefront.

Ellie continued describing her personal struggle of ongoing guilt which led to a long and challenging post-discharge journey of body disconnection and shame. Something she described that she still continues to work on healing from.

Something I will say is this: the guilt is the longest, hardest journey. One thing I want to talk about is how the guilt also turned to some inward hate for my body and how that's been tricky to work through. I think that the disconnect started when it became hard to get pregnant, and then hard to stay pregnant, and eventually the fact that we delivered early because I had preeclampsia. I can have moments where I am grateful for everything that my body was able to do to have [Tom], but for the most part I have felt very disconnected from my body and ashamed of all the ways it has "failed." I keep looking for a quick fix, but surprise- there isn't one!

Abby described post-discharge guilt turning into a guilt focused prompted by others less fortunate than herself. She stated, “Yeah. And then I, I don't know how it is for other moms. But like a part of me, I felt guilty, like, my babies are okay. But theirs aren't, you know?” Andrea also attempted to articulate her feelings about the discrepancy she experienced between getting to take her son home and knowing that other moms did not have the same fortune. She shared, “I
just... not that you feel guilty, but I think you, you're like, well, my baby was like healthy and got discharged...’’ Though she dismisses guilt in this quote, the meaning she drives towards is interpreted here as one of survivor’s guilt.

**Continued Medical Complications**

Although women were ultimately discharged from the NICU and home with their infants, participants described a continuation of difficult medical care and complications. These continued medical complications kept the women in a position of re-encountering, and sometimes integrating their NICU experiences.

Brooke described the challenge she endured attending multiple appointments each month for her daughter’s health, while simultaneously navigating her post-discharge trauma. She stated,

People are like, ‘Aren’t you happy that your baby is here? Everything’s fine now, right?’ And you're like, ‘No, it's not fine.’ It's not. I still have NICU follow-ups every six months. We have cardiologist appointments every six months. We have echoes every, you know, it's like we have all of these things.

Brooke then shared about how her daughter acquired RSV, creating more medical complications and increased ups and downs for her to navigate. She described it as a rollercoaster. She shared,

Yeah, she did okay [having RSV]. The thing is, it's like a rollercoaster [emotionally], just like everything else, with NICU kids. And so, she would do well. But she slowly declined…Needing more and more help.

Brooke gave a current update of her daughter’s health, and navigating encounters with a medically compromised child.

She is doing great. We have an inhaler to get us through the winter and when she's sick, we take it 4 times a day. She's sick right now, and so we take it 4 times today. And she's doing pretty well. We haven't had to do a quick reliever inhaler for her. We've only done her prescription. So that's good. I just hope that we can keep that up. But yeah (pause, long sigh), we have an appointment with a specialist next week to kind of get a peek at her lungs. And the whole shebang…I knew that we had trials ahead of us because she had her G-tube, and we had to get used to having a medically compromised child… She has different circumstances in her life that a lot of kids don't have to face, and, and that was like another aspect to right like, how are people going to react when they see her feeding
pump, and what kind of crazy looks am I gonna get when I get frustrated that her pump is stuck…

Ellie also discussed facing ongoing complications, including the risk NICU infants face should they contract an illness. She described the toll this aspect of post-discharge has had on her.

Right after we talked shortly, um, he got sick. Like just a normal respiratory thing, but then ended up needing a like, a nebulizer, and that.. you know, he is fine. We stayed out of the hospital and everything. But we did have like an urgent care visit, and that was retriggering, you know (voice shaking)…I just kept thinking, its different when he was in the NICU he was so much tinier, but now, if he needs an IV, am I going to have to help hold him down? It was just all this stuff, you know. Yeah, that any parent would feel. But if you, when your kid already spent a month in the hospital, it's like the last place you want to spend a night.

Reflections of Pride

Nearly all of the participants shared about their infants, exhibiting pride for the long strides their child has made in the past year. Second-round interviews revealed the ways that women integrate meaning from their experiences in the NICU by focusing on their children’s wellness, and at times even taking cues from their children to try personal growth for themselves.

Abby shared about celebrating her daughters’ first birthday celebration. She beamed as she shared about her opportunity to engage in the traditions.

I just think like, if only that's how fast it went by when your babies were in the NICU. Mine are already one…Yesterday was exactly one year since I brought both of them home. So... So yeah, yesterday we actually went to their one-year photo shoot their one-year pictures, their cake smash. I just got them back this morning [photos], and of course I'm like crying, and, because it's just crazy that you know you can go from little babies with like tubes and stuff, and you know, and then now they're like healthy and huge and thriving, and just all over the place and getting into everything. Their whole personality, is totally developed now. My chunky one (showing her daughter).

Brooke discussed seeing herself in her daughter both physically and in attitude. She laughed as she shared a story in which she described her daughter as a ‘fighter’.

She’s gonna be 2 next month. It's crazy. She is sooo sassy. She (laughter), I was laughing this morning because I had gotten her dressed. I hadn't done her hair or anything yet and I was peeking in the mirror with her and holding her, and I was like, ‘Do you want a
waffle?’ She goes. ‘No,’ and really scowls. So I scowled back, and it was like we were identical. She, she looks so much like me, and her attitude is so much like me, too. It's just like, ‘Oh, my gosh,’ Yeah, she's a fighter. She's tough. She's a tough cookie for sure, that is for sure. She is so funny.

Jessie smiled as she spoke about how much her son has grown since being so small and early in the NICU.

Yeah. He is really big. He was like the youngest in his, because he got into daycare, and he was like the youngest, but he was almost like the biggest. And now, like they transitioned to like smaller kids in his class, and he just looks ridiculously big and like he is not much older than them. And then they have like these different expectations of him, because he's so big, you know that he should be developed at a faster rate. But I'm like “He's still a baby.”

Lindsay also shared about the ways that her son has grown. She also discussed how she has integrated the experience of her son into her story and ways that integration of the NICU experience is happening as she gets to experience life with her son.

Well, I mean, I think that it's definitely just become like part of our narrative, of just our story. And, I think, well so, for example, it was just my sons first birthday. And, of course, you're always, your child's first birthday, it's a big deal. They don't really know what's going on, but it's a real big deal to you. I took the day off of work just so I could just sit around the house with him all day. I think that I was really feeling, I just kept looking at him, and I was like, ‘Oh, my gosh! I can't believe that a year ago you were, you couldn't breathe on your own. You were like struggling to clock in at 5 pounds, and a feeding tube, and all of this.’ Now he's kind of toddling around and like yelling at me so I was just really reflecting on that…And so I think there's a feeling, as far as our narrative, is coming through. On the other side [of the NICU]. And being…he's so strong now, and he was like, had this rocky start. Now he's doing so great. And feeling kind of proud, I guess.

**Longing for Understanding and Connection**

Second-round interviews revealed that women had desires for specific support during their stay in the NICU. Although the women were able to articulate the supports they had *during* their NICU stay, and ways they coped, this theme highlighted what they wished they had. Women described received support as logistical. Friends offered to help with kids, and family that was available for tasks at times. What they described wanting was a desire for connection
with other understanding NICU moms. They also described a desire for mental health support during their stay, and to be offered care by those who held a deeper understanding for their experiences. The women described wanting to be offered physical, emotional, and mental support which would support their own holistic wellness.

Ellie described her desire for someone to hold space for her emotional experience with guilt, rather than bypassing her feelings completely.

It’s like, you can say that (you feel responsible), and then people want to reassure you like, ‘It’s not your fault.’ And that's nice, and I get the sentiment, but, just holding space for that feeling would probably go further.

Finding Meaning

When navigating the Deep Dark Battle post-discharge, participants worked to create meaning out of their experiences. For many of the women, this presented as opportunities of advocacy and to share hope with other women navigating the NICU. Each participant shared aspects of importance to them as they worked to make this event a more constructive and integrated part of their story.

Jessie shared how offering psychoeducation about the NICU to family members was meaningful. Psychoeducation and consultation were something she felt was lacking and she deeply wished for during her experience. She shared this story:

I think, being maybe more… I guess for me, like I said, I didn't really know. I think I said this before, I didn't know too much about the possibility of being in the NICU, and there wasn't a lot of psychoeducation around that. And so I had a cousin that just had a baby, and a lot of the conversation we had, was because she was very high risk, and they thought they were gonna have to deliver him at like 21 weeks to where… his chance of survival was minimal. But he ended up being able to go to 38,…37 weeks. Yeah, and ended up healthy. But they had to do a NICU stay, and so, I think just having a different appreciation for just NICU moms. And then that whole process. But, I think just preparing my cousin like in talking with her was important.

Ellie also shared,
I will say that shortly after [Tom] was born I couldn’t imagine ever going through it all again. I kept saying that I would never want to put another baby through all of that. But with some time and distance from our NICU journey, I don’t have such a visceral reaction anymore. I’m aware that even though it was hard to watch him have multiple IVs and being poked daily, it really was just a blip on the radar of his life. He absolutely was worth it and honestly, he doesn’t know any other way of starting out life (nor will he remember). So, I’m glad that my opinion on that has changed. I would tell a NICU mama that she may feel like that initially, but it doesn’t mean that she’s always going to. The guilt does decrease…at least it has, for me.

Lindsay discussed her experience making meaning by reframing her trauma into a reflection of personal strength, a story of survival. She shared,

Then it's like the further out that you get from it, you can, you think more about the feeling of, ‘Oh, we overcame.’ Versus like really dwelling on the like minutia of all of that hard stuff. I think that’s important just for your own emotional health. The way you think about it. Not just diminishing it or dismissing it, but that when you look back and think on it, it is almost like a positive thing. Because you're thinking about how you got through that. And how you were strong through all of that.

Brooke had much to share about ways of making meaning of her experience by reflecting on the ways that this extremely challenging and difficult time morphed with distance from the NICU into strength, and a catalyst to be a better person in all of the aspects of her life.

I actually think about this a lot. As you know, my mom died when I was young. I was raped shortly afterwards. And this trauma with my daughter. And as horrifying as all of those things are, those experiences have made me a better person. So, even though I am obviously still emotional about so many things, and especially with my daughter, that experience [NICU journey] has made me a better person. It's helped me to see how necessary it is to be fully present with my kids. Because, I very easily could not have had that with her. It's made me a better mom. It's made me sometimes, most of the time, it makes me a better wife. Sometimes I get annoyed, but most of the time it's made me a better wife. I’m thankful that I'm to a place where I can acknowledge that those experiences that made me a better person, because I know, that there's a higher calling other than connecting with someone socially. I feel really passionate about actually like starting a group at [Hospital], and hopefully like getting that rolling and making sure that that happens.

She went on to share about integrating her experience in the NICU by reflecting on how it has changed her ability to experience her range of emotions and allow them to be okay.
Maybe this also made me not only a better mom, but a better person. In that, I'm able to
acknowledge when I need to set boundaries. So, when I need to really lean into the things
that make me feel good, and also not try to push the feelings away. And it's okay to
acknowledge that [the feelings].

Andrea described finding meaning by passing forward moments of connection and care to others
journeying through the NICU.

The way I felt is, could be completely different from the way you know other people are
feeling, and how they manage going through the experience, but the least I can do is just
be like, 'Hey, I've been there. If you want to talk about it, or vent, or even like a year from
now, you want to just like talk about it . . .' Because I feel like it took me a like a long
time to kind of, be able to, and I still have a hard time kind of vocally explaining how I
feel in that situation, because I think, do you just sort of internalize them [feelings], and
just like, push them really down. You know what I mean? I think mainly nowadays just
reaching out when someone's kind of going through the same situation... Yeah, and just
not trying to compare experiences, but just, you know, be like, 'If you ever just wanna
vent, or if you want to talk about it, or you want me to hear your story, then, you know,
I'm here.'

Messages to Future NICU Moms

In second-round interviews participants were eager to share messages to other women on
this journey. They offered words of wisdom which touched on many aspects of the Deep Dark
Battle. Women reflected on pieces of advice that could have combatted the downward internal
spiral they journeyed. These messages reflect the experiences they hope to alter for future
women, giving them a possibility of a more constructive experience. Women shared about the
strength it takes to be a woman and mom while having an infant in the NICU. These messages
include: Your Experience is Valid, Ask for Help, and Take Care of Yourself.

Andrea offered a beautiful summary to other women on this journey:

This is going to be the hardest thing you're probably ever going to go through as a mom.
And it's gonna feel like the most traumatizing, horrible experience as you're going
through it. But you know your baby is where they need to be to heal and to recover, and
that you know you just have to trust the process... whether your baby is in the NICU for
a day, or whether your baby is in the NICU for 10 months, you know, I think, of course,
the experiences are different, but I feel like, no matter what it's worth it to have your
baby. You know they're where they need to be. And it feels like the most traumatizing part of your life, and it is. But you know, you get through it, and then there's nothing but like amazing fun experiences and then it's something of the past. It's not something that ever really goes away, but it kind of is something, it's just like another thing that happened. And it feels like, you know the days are sooo long and agonizing [in the NICU], but then it's like one day you wake up in a blink of an eye, and your baby is six months old, and they're accidentally rolling off the couch… Just sometimes things like that feels like time is going by so slow, but you're gonna wake up one day and say, ‘Oh, my gosh, my toddler's about to be 2. How is this even possible?’ Yeah, so hang on. It could be a bumpy ride. But eventually, you know, you get to the end of it [NICU].

Jessie shared her hope for other mothers to know, “It takes a special kind of person to being a NICU Mom, and a certain type of strength. And even when you don't think you necessarily have the capability of being one. You do.” She went on further to offer, “Sometimes it's just as simple as taking it moment by moment, and reminding yourself that you're doing the best you can.”

Abby offered a piece of encouragement for moms who have other children at home. “Yeah. And I think the other thing is, I was so worried about my other kids, and I would tell, if it was another mom that had other children; kids are resilient and it's temporary for them.” Brooke also offered hope of just making it through, “That they can survive? Right? Like it'll feel like you're losing everything. And you might: right, because it's a very real possibility that your baby won’t make it, but that you'll survive… just that they [other moms] can survive, and that they [other moms] can do it.”

**Your Experience is Valid**

Many of the participants shared messages which offered validation to all of the experiences a woman may be navigating. They discussed the reality that it is a scary and hard time, that feelings about how long the experience is are valid, and they pushed again making competitive comparisons which downplay the woman’s experience.

Abby, shared about the validity of the experience that any woman faces while in the NICU.
I feel like regardless what anybody's situation is, or why they ended up in the NICU, it doesn't...I don't know what the word is... it doesn't like make one person's situation less painful than the other. I think, regardless, even when people are like 'Oh, my baby, only had to be in the NICU for a week.' And then, 'oh, but mine had to stay for a month.' It's doesn't matter. A week feels like a month. A month feels like a year. It is all painful. It's all awful. In that group that I’m in, I've had moms say, how one of their babies had to be in the NICU for almost a year, and it's like God I could not imagine. But it's also like ‘It felt like a year to me.’

Brooke offered a simple validation and warning to future moms. She shared, “That it's really scary and really crappy. But also, really lean into that feeling vulnerability so that you can really enjoy those really high highs.” Lindsay hesitated to put advice out, knowing that every experience is different and that the experience varies across situations. She expressed, “I guess I kinda stumble a little bit…on what I would offer, because, each woman's experience is so different, and unique to her. But I guess you just want them to know that however, they feel is okay.” Lindsay continued on, “I guess that's what I would want too. However you’re feeling is okay. If you're feeling really scared or really mad., or full of... or happy, you may be blissful because your baby is here, and you're feeling all of those things. That's all valid feelings. These are all valid feelings.”

Ask for Help

Four of the women offered encouragement to women to ask for help, despite the internal difficulty it may present.

Lindsay shared her reflections about asking for help and finding that people were waiting and wanting to offer support.

Yeah, and ask for help. Because that can be kind of hard to do. Yeah, that's what I would want other mothers to know. It's okay to ask for help. I mean other people want to help, it's hard still to ask them. You don't want to feel like a burden, but I think that it's important to ask for help if you need it…Right, because a lot of times people want to help you. They just don't know exactly what you need, and sometimes you don't know what you need in big situations like that, because it's your like processing… but, certain things,
you do know. Like I need somebody to, pick up my child from school. Go ahead and ask them. When people say ‘anything you need.’ They mean it.

Similarly, Abby also offered advice about asking for help for other children at home. She shared, “Ask for help for your other kids. They’ll miss you, they’ll probably struggle, they’ll have a hard time, but they’ll get through it just like you will.” Ellie reflected, “Find a way to ask for help and accept the help (begins crying). Because I think that's probably the biggest struggle.” Similarly, Jessie stated, “Reaching out for whatever support you can during that time, even if it's minimal support. There is a lot of great opportunities out there for it.”

**Take Care of Yourself**

Final messages from participants to other women enduring the NICU were encouragements to take care of themselves. Despite the lack of available support around them, women reflected that had they done a better job of caring for their whole selves, the experience may have been different.

Jessie stated simply, “And (pause) I think it's important to take care of yourself through that process just as much it is to take care of your baby.” Abby also shared her thoughts about taking care of yourself. “You gotta do what's best for your mental health.” She continued on in detail,

Don't worry about what other people think. Don't worry about if people are saying, ‘Oh, yeah, she just kind of forgot about her older kids.’ Or ‘Oh, she never goes up and sees the babies enough,’ You know, I was always asking the nurses, ‘Do you think I'm spending enough time up here?’ And it's like, you're spending the time that you can, so that's enough.

She discussed the goal of seeking to find peace during this stressful and scary time.

And so, I think that's important. I think you need to realize. Okay, what is it that's gonna give you the most peace of mind? Is it going to be home with your family, and just let the nurses do their job? Or is it going to be there with your babies, and you knowing everything that's going on, and every little thing that's happening and being super involved? And you need to do whatever that is, and however you see that fit.
The post-discharge experience was described by women as a time for unpacking their NICU experiences. In this theme women identified having to navigate their trauma and work through deep anxiety and fear for their infant. They described continuation of guilt and fear of death that they had to move through. They also identified and described some positive aspects of their post-discharge time. They identified reflecting on their own strength and pride for their infants. Women then offered messages to future NICU moms. Many of these messages came from places they had wished for themselves. They reflected their own desires for these aspects that may have softened their experiences. Women encouraged other women to know their emotions and experiences are valid, to ask for help, and to take care of themselves.

**Conclusion**

Chapter IV described round-two analysis. The themes of: Entering the NICU, The Forgotten Mother, The Juggling Act, The Pervasiveness of Death, The Deep Dark Battle, Escaping the Spiral, and Post-Discharge – Integrating the Deep Dark Battle were strengthened in more detail throughout second-round interviews. Within each of these themes detailed depictions of the Women’s experiences of navigating the NICU emerged in subcategories. Chapter V will integrate and synthesize the data of both rounds of interviews. Women offered clarifying details and extra data about all of the superordinate themes. Round-two interviews provided an increased felt depth with women’s experiences with The Pervasiveness of Death and their experiences with their post-discharge experiences. Specifically, interviews gave rise to women’s insight about their fear of facing death and the tax this fear and uncertainty had on them. This new data displayed where women began to move away from the external focus of The Juggling Act and into their own internal emotional experiences before heading into the Deep Dark Battle. Round-two interviews also magnified how women experienced post-discharge.
Data from round-two provided clarity about how women began to integrate their NICU experiences, by having to sift through their trauma responses, fear and guilt. It also highlighted how women faced continued medical complications for their infants. Finally, round-two interviews helped identify where women began to find meaning, and reflect with pride and messages of hope to future NICU mothers about what they wish they had known.

Chapter V: Results

Six women who had infants in the NICU participated in this study. Participants engaged in two in-depth semi-structured interviews which lasted between 30-90 minutes each. I transcribed the data to develop further engagement with the data. When beginning data analysis, I first read transcripts as a whole, in order to become familiar with the data. This practice allowed for a more intentional absorption of the data. I then conducted three rounds of initial noting of data. I analyzed the data from descriptive, linguistic and conceptual perspectives. After initial noting, I began to code emergent themes. I used interpretative analysis as I explored initial
noting and developed codes from the data. I did this for each transcript and then across cases to
develop superordinate themes (Smith et al., 2009). A member check was presented to
participants for review following the analysis and writing of second round interviews. The
women’s feedback was integrated. This chapter presents the results of the phenomenology of
how women make meaning of their holistic personal experience having an infant in the NICU.
Results indicate categories of **Entering the NICU**, and challenges of being bypassed and **The
Forgotten Mother**. Women described the external pressure they navigated as they managed the
Logistical and Mental and Emotional Tasks of **The Juggling Act**. Data analysis also revealed
experiences with **The Pervasiveness of Death** and women’s internal emotional struggles in **The
Deep Dark Battle**. Women discussed finding supports and coping strategies **Escaping the
Spiral** of difficulty. **Post-Discharge**, women reported a continuation of the NICU experience as
they worked to **Integrate the Deep Dark Battle** outside of the NICU. Figure 2.1 represents a
visual of the results of the major categories capturing the phenomenology of women’s
experiences in the NICU.
Figure 2.1

Results of Women’s Experiences in the NICU

Note. This model shows the process that women move through as they experience being in the NICU with their infants. They begin with a sudden Entry into the NICU. They experience being bypassed and overlooked in The Forgotten Mother. Women are faced with tasks of The Juggling Act in which they manage external Logistical, and Mental and Emotional Tasks. As women face The Pervasiveness of Death that the NICU holds around them, they begin to look inward. Next, women moving into the internal downward spiral of the Deep Dark Battle. Women use supports to move out of this internal space and then experience Post-Discharge integration of their experiences while in the NICU. The arrows show the movement through process of the phenomenology.

Entering the NICU

Entering the NICU is the starting point of this process and event. Participants offered their experience of suddenly and unexpectedly delivering their infants and watch them be taken to the NICU. They discussed their internal experience of grieving lost moments with their infant, and then quickly having to learn and adjust to being a NICU mom.

Sudden and Unexpected

Women described their infant’s admittance and the turn of events leading to the NICU as sudden and unexpected. Ellie described the abruptness of her entrance into the NICU,
We didn't have, because everything happened so fast, and because he was eight weeks early it wasn't like we had the car seat in the car… You know we didn't have a hospital bag packed, like it was just kind of… I went to the hospital. I had a baby.

The participants described a *disruption to their pregnancy* and then suddenly being placed into the NICU with their infants. Women shared about being unprepared and surprised. A prominent part of what emerged for women was their experience of *entering birth alone.* Whether participants were entering alone because they couldn't get their support people there in time, or they were being life flighted to another hospital, birthing alone was not part of their plan. Women also expressed expecting to be able to have more support during their deliveries.

**Loss of a Dream**

After the initial surprise and entry to the NICU, women described experiencing a *Loss of a Dream.* In this subcategory women had hoped and planned to give birth to their infants, articulating the stark differences between these dreams and how being in the NICU lead to a loss of the first moments and days with their infants. Instead of snuggling and taking their infants home, women described grieving lost moments, lost connections, and pain of being separated from their infants. Women grieved what they thought would be, and worked to accept what was. Jessie shared her dream of the first moments with her infant being replaced with separation and sorrow.

I told his Dad to go with him to the NICU, and then I got left there (laughter), and then brought to the [post-op] room. So, we were separated. I didn't even get to like, touch him, or really see him until the next day. In the moment it was really hard, I think, just thinking about not having that immediate interaction, because you have this like *dream* (emphasized) of like, ‘Oh, when I meet my baby it's gonna be this beautiful moment,’ and it was like the opposite.

**New NICU Motherhood**

The last aspect of **Entry into the NICU** is the subcategory of **New NICU Motherhood.** This was articulated by women as a time of learning what the NICU is. Women described
immersing into the environment. They shared about their rapid intake of NICU procedures and the medical interventions their infants needed. In this subcategory, not only were women navigating the roles of motherhood (some for the first time), but also how to be a Mom to a NICU infant. After women adjusted to their rapid entry into the NICU they faced a new set of challenges. These challenges surfaced in the experience of being The Forgotten Mother.

The Forgotten Mother

The next theme that women experienced in the NICU is The Forgotten Mother. Here, participants were bypassed or overlooked both personally, and in their maternal role. The women shared about their need to be cared for emotionally, physically, and mentally and shared experiences of how these needs were bypassed. Women explained observing staff’s focus to treat and help their infants survive, while also not integrating or attending to the mothers’ emotional or personal needs and at times not integrating them into the holistic care of their infant. Brooke summarized this by saying, “I feel like Moms are kind of forgotten in the NICU in general. Right? It's like, ‘Oh, you had your baby early, you’re in the right place for them to survive.’” Andrea shared her experience of finding that even clinical support is not aimed towards the woman. She shared,

And I just feel like there isn't really, I mean, there's the social workers, but they're not really there for you... And I don't even think I met our social worker. She, I think just read our paperwork and like called me one time to make sure that we had oxygen lined up at home and we had a ‘fit’ (up to code) house, too. Yeah, and that was it.

Subcategories of The Forgotten Mother include Overriding the Mother Role, Detached and Dismissive Staff Responses, Infrastructure Collapse, and Frustration with System Communication.

Overriding the Mother Role
This subcategory magnified participants’ experiences of being displaced from their mothering role during their infant’s time in the NICU. Women described a deep desire to engage in caring for their infant and at times having their caregiver role ignored. In some instances, the experience of being overlooked were presented by staff in ways that appeared as “giving back” rather than “taking away.” For example, staff offered encouragement for women to rest and heal. Although well intentioned, women described feeling misunderstood as their role as mother was forgotten. They articulated staff overlooking the tax of being asked to step away from their maternal role. Lindsay described it as,

Then [the staff] tell you like, ‘you really should sleep.’ But you want to be there. It’s like, ‘Should we stay?’ And they're like, ‘No. you should go home. You should sleep and set a timer and pump throughout the night. And just do that in the comfort of your home.’ Which just felt like, ‘Really, I should do that?’ I, I don't know. It felt wrong.

**Overriding the Mother Role** emerged in direct and covert ways. Participants acknowledged staff performing infant caregiving because it was easier, more aligned with staff expectations, and consistent with hospital protocols.

**Detached and Dismissive Staff Responses**

In this subcategory of The Forgotten Mother, women experienced being personally and blatantly disregarded or dismissed by staff. Women received messages from medical staff that their needs were burdensome or bothersome. Jessie described staff communicating annoyance with her need to see her son,

She was very kind of rude, passive aggressive, was kind of like not (long pause) she didn't put me first like, ‘Oh, let's bring you to meet your baby for the first time!’ It was kind of like, ‘Well, if you want to go and meet your, or go down to the NICU, this would be the time to do it because I have to help you down there and have to stay with you and then bring you back.’

Participants noticed **Role Rigidity** with staff and experienced an emotional handoff when women sought emotional support. Women articulated how staff were “black and white” in their
role to provide medical care to infants and avoided maternal care, seeking ways to hand women off to someone else when their emotional needs became too prominent. Andrea described her experience of the emotional handoff she experienced.

I had plenty of mental breakdowns when I was there. Like, clearly, I was very (trails off) ... I had, I think she was just a lactation consultant and nurse, walk me back to the room and be like, ‘Do you need me to call somebody?’ and I'm just like, ‘well, I...’ She was referring to my husband. I'm like, ‘Well, no. That's not going to help.’ I mean he's not gonna really... I feel like, especially your spouse, doesn't really know the right things to say in, in those times, and especially, I think, as like new parents, too. Like he was, he coped a completely different way than I did.

Infrastructure collapse

Infrastructure collapse illustrates how women’s personal care was forgotten or overlooked due to breakdowns in the physical and personnel infrastructure. These systemic misses led to the bypass of basic care for women. Participants shared about not being oriented to the hospital in order to engage in basic hygiene. They described having challenges with physically getting from labor and delivery to the NICU, and encountered mental and emotional tolls from the open bay rooms where they received care. Andrea shared this example of the infrastructure collapse women experienced due to open bay rooms.

The shared room was very stressful. I mean, because it is a big open room and there's just a curtain more or less. We had some, we were really advocating for our own room, we just go there is a baby and a parent and it was I think, a caseworker situation. Um, And, it just like made us feel very uncomfortable anytime the mom was there. She also described the physical discomfort she faced in open bay rooms. “I'm basically sitting in a chair like this more or less (cramped over) with a stool and like taking naps, you know, sitting up with like, my neck kinked, like trying to pump in there too.” She highlighted the fear that open bay room and multiple sounding alarms also added to the experience.

I think the added anxiety too was, you know (slowing down), hearing all the alarms going off and you know, they have your baby's primary screen, but you can see every other
child…And when like a stat drops or, and you see like, and you hear the alarm and in just hearing those alarms too just makes you like, ‘Are the parents there when this is happening? or in, you know, it's so many thoughts like run through your head, and the alarms.

**Staffing challenges** also presented a collapse, and continuity of staff was lacking. Abby shared her experience with this.

And for me the other thing is, I had all kinds of nurses. I never had the same nurse. I did for maybe a couple of days, and I would request her. Then I had traveling nurses and other nurses. I had nurses that would come from different floors and departments. and I'm like ‘Well, do you even know how to do a CPAP on a… like they're tiny.' And so, it was nerve racking for me because it's like, I didn't want to question their skills or their training. But at the same time, I’m like ‘This isn't your specialty. I want the best. I want somebody who has experience you know, working with my child and their feeding tube.'

Women also identified difficulties with shortages of specialty staff such as lactation nurses and the barriers that COVID complications presented with regards to staff availability. Andrea shared her disbelief in the oversight of women’s mental health, marking another aspect of infrastructure collapse. She shared,

It's amazing (sarcasm) to me that…And I think we talked about this in our first interview, too, just not really having like the professional help that you need. I think, in the situation where you're… I mean hopefully maybe this this study will, will help, you know. Help that… But it's just kind of amazing [negative amazement] to me that…I know your OB isn't necessarily your provider per se, and they aren’t in the mental health realm of things… but it's like at the same time, you'd kind of think when you’re... I mean your OB knows your baby is in the NICU. So, wouldn't you…is there like no way to just automatically be like, ‘Hey!’ At your one-week post op or post appointment like, ‘Do you want me to refer you to someone just to help you cope? Or even down the road?’ Like, ‘Here's a number.' Or just something. It's kind of amazing that you're not even offered that.

**Frustration with System Communication**

Women experienced being forgotten in the communication with the medical system.

They shared about their exasperation from the absence of communication. Some recommended more communication in the form *NICU prep while Pregnant*, articulating frustration with the
lack of education and preparation about possible entry into the NICU during their pregnancies.

Jessie offered an example of this when she shared:

I think one thing was being not told anything in regards to like, you know, when you're doing your prenatal care, nobody says like there is always a chance [of receiving NICU care]. You could have your baby early, and so just like not knowing anything, about the NICU.

Women also expressed challenges with Communication of Treatment Plans and Changes with their infant’s care. Here they described feeling left out of medical decisions. Abby offered an example of the lack of communication about her infants being moved to a different room. This magnifies the distress that the lack of communication by the system created during women’s NICU experience.

Well, I didn't even know that…I went to go see them. The nurse took me in there to go see them, and they weren't in there. I started panicking and freaking out and crying, and I'm like, ‘Where are my babies?’ Yeah, and nobody knew where they were. Until they were like asking around, asking around. And I’m like, ‘Yeah, this is where my kids were. They were right here in this corner. They're no longer here.’ Then they're like ‘Oh, hold on, let's find out! Hold on,’ and I’m just like what do you mean find out? Like... So, I thought like something happened to them, and nobody told me. You know that was my first like gut feeling...So then they're like, ‘Oh, no, no, no, they're upstairs.’ So, then I was like, okay (exasperated).

The Juggling Act

The Juggling Act is the third category of the phenomenology. Women revealed the many tasks they had to manage during their infant’s stay in the NICU. This theme is about doing, rather than feeling. The balls that women juggled were a way to keep their focus outward rather than having to look inward. By focusing on what needed to be managed there was a comfortable distancing created from having to address their own internal emotional experiences. Two main areas were identified in the Juggling Act. The first subcategory is the Logistical Tasks that women had to maintain. These included self-sacrifice (putting themselves second to baby), work and finances, and the logistics of scheduling. The second aspect of the Juggling Act is the
**Mental and Emotional Tasks** that women were handed as they navigated the NICU. These include the task of managing their emotions to maintain proximity to their infant, being alone for long hours throughout the day, and enduring the nonlinear medical progress of their infant. The properties of **The Juggling Act** are depicted in Figure 3. Lindsay described the emphasis of the juggling act as “doing” with a continued focus outward.

Because I was like juggling so much that it, that it, you know (pause). I think I was, you know, still somewhat taking care of myself and managing to do what needed to be done. And take care of [Sage], yeah, and pump. It was like, really, I'm doing all my jobs. The things that I can do.

**Figure 3**

*The Juggling Act*

![Diagram of the Juggling Act](image)

Note. The Juggling Act has two subcategories, Logistical Tasks and Mental and Emotional Tasks that women are faced with managing. Logistical Tasks include Self-Sacrifice, Work & Finances, and Schedules. Mental and Emotional Tasks include: Maintaining Proximity to Infant, Alone, and Nonlinear Medical Progress.

**Logistical Tasks**

The **Logistical Tasks** of the Juggling Act are the balls that women had to work with (and around) in order to keep being able to show up and be present for their infants in the NICU. Women articulated *Self-sacrifice*, resulting in women forgoing their own personal needs. Self-
sacrifice is where women ignored their own needs: physical, nutritional, basic hygiene and self-care in order to be available to their infants. *Work and Finances* were other tasks women had to address and manage. They shared their feelings of stress about missing work and described unexpected expenses and strains from receiving NICU care. Another logistical task that women focused on were *Schedules*. This was where women were often tasked with addressing how to manage their day of being in the NICU while also having other jobs, and sometimes children at home, in addition to a variety of roles that required their attention and time. Energy was focused on organizing, arranging rides, work tasks, pumping, navigating decisions about where to be when, attending to other children’s needs, and deciphering how to be a NICU mom and partner. Brooke shared her experience with the logistical tasks of needing to be in the NICU and simultaneously with her child at home.

So, I was there until, because I treated NICU kind of like a job, right? Because we live in small town and [first child] is a little guy, so I still kind of wanted to make sure his routine was still the same. So, I would take him to daycare, and I would head to NICU and then I’d be there until five normally, and then I would come home.

These logistic tasks all took a toll on women while simultaneously keeping them focused on external factors, rather than their internal emotional experiences.

**Mental and Emotional Tasks**

The *mental and emotional tasks* of *The Juggling Act* have an element of mental and emotional endurance while remaining externally focused on managing the task at hand. Although there was focus placed on mental challenges and emotional experiences in this subcategory, the experience remained external and separate from women’s internal processes. Women’s emphasis remained on what needed to be done and the mental and emotional tasks of how to ‘keep going’ to be present for their infants. Women described the task of *Maintaining Proximity to their Infant*. Here women were managing being separated from their infants by finding
alternative ways to bond and remain close and connected to them. Abby identified feeling disconnected from her infant and sought support from a social worker to address the distance between she and her infant. “And I just told her (social worker) I already feel like I’m getting postpartum depression. I already feel like I’m having a really hard time because I don’t feel like I’m able to bond with my babies.” Another mental challenge women had to manage was being alone. Here women focused on enduring long days in their rooms alone, and feeling like they were on their own to figure out the environment. They described feeling alone in figuring out how to manage their lives and how to be available to their NICU infants. A final mental and emotional management task was enduring and accepting the Nonlinear Medical Process of their infant. Women described having to accept and adjust to rapid changes each day. The energy and focus towards their infant’s health and medical situation allowed women to avoid their own internal emotional experiences about being in the NICU.

**The Pervasiveness of Death**

The Pervasiveness of Death theme developed fully after round-two interviews. In round one, all of the participants hinted at the nature of the NICU being emotionally heavy and frightening due to the possibility of death. However, no one named their fear or experiences with death. In round-two interviews I asked deliberately and directly about the impacts of the possibility of death for their own infant and other infants in the NICU. Participants bravely shared their deep worry and fears despite many rules and norms that prevent us from speaking about infants dying. They shared emotional distress knowing infants were dying. They also described feeling guilt and suffering for other mothers. Brooke summarized her experiences with the Pervasiveness of Death.

I had to really just not allow myself to go there [to death], because when I did it was… it was desperate. It was like a desperate, all encompassing, feeling that I couldn't get out of.
And having experienced that like a couple of times while we were in the NICU, I just needed to not let myself go there.

Similarly, Andrea described her experience of shock and the realization of death around her. She stated:

You think, ‘That doesn’t look good. This is not looking good [about babies around her].’ And I mean, there was a few babies that [death] happened while [Sam] was in there. And so, I think that that was like, a pretty traumatizing thing. And you just want to give like a parent a hug. And you know, it’s very… I feel like you’re also in a daze.

**Fear of the Unknown**

Women articulated *Fear of the Unknown*, anxiety about not knowing what future outcomes awaited their infants. Here, women confronted the possibility of, and the uncertainty whether their infants would be okay. Ellie shared about her experience where fear left her in a spiral of questions, evaluating her son’s proximity to death. She shared, “So, every little lab value, ‘Okay, his platelets dropped a little. Does he have a brain bleed?’ There is just always that overarching fear of ‘What is it?’ You know, ‘How close are we?’”

**Preparing for the Worst**

Women also spent emotional energy *preparing for the worst*, taking in data and using comparisons to mark their infants’ health and proximity to death. Participants experienced distress and worry for their own infant as they took in information about the possibility of sick and dying infants. Abby offered an example of this experience.

we were in like a huge room with little, the beds everywhere, and I would go in several times a day, and there would be babies there. Then, when I would come back there wouldn't be, and I didn't know what happened to them. I didn't, I don't know like, ‘Oh, did they graduate and get to come out of the NICU or did they die? Did something happen to them?’ And one baby did end up going into cardiac arrest when I was in there, and they had to ask me to leave. and so that… (silent and tearing up). It is (tragic) (crying) because, it's like as a mom you don't want that for anyone. And then you know, it just makes you worry like 10 times more about your own children.
Self-Preservation via Compartmentalization

The subcategory of Self-preservation via Compartmentalization also emerged from round-two interviews. This subcategory highlighted the ways women attempted to separate from the intensity of fear in the NICU in order to continue being present for their infants. Several aspects of compartmentalization emerged. Private rooms offered a physical opportunity to be separate from the intensity around them. Women also experienced separating emotionally from the possible outcomes in order to continue functioning. Brooke offered a description of how this compartmentalization served her to continue being present for her daughter.

While I have big feelings, and I'm super passionate, and I'm willing to express those feelings, when it gets bad enough I compartmentalize right? So, I am like, ‘Okay. This [death] can happen. I have to stonewall. Protect myself.’ So, I can acknowledge that it happens, I think that's why I have like such intense posttraumatic feelings. Because I've had to compartmentalize in those instances.

The Deep Dark Battle

The Deep Dark Battle is the internal emotional downward spiral that comprised the core of women’s experiences in the NICU. All of the participants identified feeling aspects of isolation, and engaging an internal battle with guilt, failure, and helplessness. The spiral inward is comprised of subcategories of Lonely, “Good mom/Bad mom Dichotomy”, Guilt, and in the deepest aspect of the experience, a sense of Failure, Shame, Despair, and Hopelessness. Figure 4 depicts the aspect of the downward spiral women experienced.
Participants expressed their experiences of being *lonely*. Here, women shared about being in the midst of inner turmoil that others could not understand unless they had endured the NICU experience as a mother. Women described being disconnected from others emotionally, and alone in their sorrow. Andrea described this in both first and second interviews. She stated, “Yeah, I mean, I think my biggest thing, I think I told you in our first interview, I felt so secluded...
and kind of … You know you feel alone. Like not many people really experience what you experience.”

Abby also shared her experience of feeling emotionally lonely and having guilt asking for help, she shared:

Oh, it was extremely lonely. That part [being on her own]. Yes, that was extremely, extremely, lonely and isolating. I had a hard time even asking for help. I would feel guilty asking my mom to do stuff. And, there was no one to talk to. No one. But it was so hard, and it was so isolating, so isolated.

**Good Mom/Bad Mom Dichotomy**

Internal messaging by the women was prominent during The Deep Dark Battle. Here, women narrated the stories they told themselves about what comprised “good moms” and “bad moms.” The messaging was “all or nothing” by nature, and left little room for women to be successful. This dichotomy of messages added pressure to women as they internalized rigid messages and battled internally with themselves. Women articulated messages of Good moms pump and produce milk, Good moms are present, Good moms are selfless, Good moms don’t need to ask for help, and finally women articulated examples of what “bad moms” engaged in. “Bad mom” behaviors emerged in women’s judgement towards moms who weren’t present at care times, towards themselves when they were unable to help or fix things for their infant. Abby articulated this when she shared about her gratitude for working for herself in order to be present for her daughters. She shared, “I would be like a lot of those other moms, and have to just come once or twice a week or a couple hours a day, and that’s it.” This negative narrative towards other moms also emerged as women described their surprise at the variety of people entering the NICU, implying that their previous judgements about NICU moms held blame or fault.
Ellie described the messages she gave herself about the kind of mom she was because of a decision she made to leave and later was unable to return to the NICU as planned. She shared,

And that was just another moment of like, ‘Okay. See?’ You took a couple hours for yourself, and like, ‘See what happens?’ Like...which isn't even true. But you know, that's what it felt like at the moment. Like just a reminder that this is why you can't let your foot off the gas. You have to beat yourself, up every hour, of every day.

She later reflected on the deep pressure she placed on herself to be a good mom. She described self-judgment and lasting guilt for not succeeding at the task she perceived was her job.

The self-judgment and like, critic...I just I wish I could go back and like, be kinder to me... I, I, think I’m still on the journey of forgiving myself (begins crying), forgiving myself for, I think just the responsibility of (pause), that's the thing about being a woman is... It's all on you, you know? Like to get them here, to get them here safely, and when that doesn't go to plan it, just the guilt is like...you know?

Guilt

The experience of guilt emerged as a poignant aspect of what women were sifting through in their battle. Women shared how they experienced guilt in many arenas of their lives. They faced guilt watching their infants struggle medically, and when making decisions about how to use their time and availability to be present with their infants. Some women had the impossible decision of choosing between being with children at home or being present in the NICU, resulting in deep feelings of guilt. Abby described her guilt of feeling torn between the NICU and her children at home. She described, “I just felt so so guilty when it was time to leave [the NICU], and I would cry every single time (crying again) … and then I cried a lot. Because, I felt like I wasn't being attentive to my boys’ [at home] needs as well.” Abby later expressed guilt about feeling torn. She said, “The guilt of, ‘I'm not spending enough time with all of my kids.’ The guilt of, I can't take them home. I can't be there for my older kids. I can’t be involved. How I need to be as a mom.” Ellie gave an insightful statement about her experience with guilt and her desire for support around this. She stated,
It’s like, you can say that (you feel responsible), and then people want to reassure you like, ‘It's not your fault.’ And that's nice, and I get the sentiment, but, just holding space for that feeling would probably go further.

**Failure**

The experience of *failure* emerged as a deep suffering for women. Women identified thoughts of being the *failed vessel*. This experience of their body not doing the job it was “supposed” to do regarding growing a healthy, term infant was pervasive. Jessie described this when she shared,

> I think the only thing that you know has come up through this process was like having, I think we talked a little bit about the shame of not being able to like carry him, in like the right way. As a Native mom trying to embody, you know, like overall health and well-being, I think it was just really important for me to limit my stress in my environment. The stress in my environment and everything. Taking care of my body, by like eating right and exercising. Some of those things like I just wasn’t attending to, that like led to that. And so, I think you know, when thinking about, maybe not necessarily for NICU Moms, but just mom's, you know, new moms or pregnant moms in general, is just listening to the doctors and tending to yourself, and really just so that it doesn't lead to these high-risk situations.

Women also described a sense of failure surrounding their *Helplessness*. They identified their inability to help their suffering infants or contribute in a way that made a difference. Women shared how their lack of agency and perceived inability to be a mom to their infants was disempowering. Lindsay described, “I felt really, kind of, you know, helpless or useless. I mean (pause) to just be in a situation where we can't really like exercise, a lot of control. There's not much to do to like direct the outcome. It's hard. So that was that was the big challenge. I just felt like that was just really hard.” The experience of failure was followed by women’s experience with shame, as they continued on in their deep inward spirals,

**Shame**

*Shame* surfaced in this study as the deepest sense of self-blame and failure. Women identified feeling responsible for their infant’s medical state and admittance into the NICU.
Participants self-narratives surfaced with stories of absolute ownership of failure, and thoughts that something was ultimately wrong with them. Ellie details her sense of responsibility and the shame she navigated about her son’s early birth by cesarean and placement in the NICU. She stated,

‘Oh, maybe I got this wrong. Maybe he's not as safe out here, and maybe he should be inside, and maybe I should have...’ You know, ‘What could I have done different?’ And that whole loop. So, I’d say for me it was, it [shame] was delayed. It was like a honeymoon period of a couple of days where I just really felt like, you know it was fine. And then yeah, and then....

Despair and Hopelessness

At the inmost recesses of the downward spiral of The Deep Dark Battle, despair and hopelessness were present. In this subcategory, women moved away from self-blame and refocused their energy towards the medical system, frustrated and desperate to get their infant home. Ellie articulated her experience of feeling desperate and simultaneously trapped, “Yeah, it was, yes, it was really tough there towards the end. Like I just felt like we were like stuck in purgatory. We were never going to get out of there. We were never going to get off the IV.” Lindsay described her experience of guilt about wanting to be in two places at once between her children. She shared about losing experiences in both places. This pressure ultimately led to her desperation to get home.

When I would be at the NICU, I would be like thinking about my son at home, or feeling like I needed to be at home, and then, when I would be at home, I would be like rushing through things and thinking like, ‘Okay. Well, we just have to get back to the hospital. We just have to get back to [Seamus] and um, and it's really terrible how you how you do this to yourself, because then you have like being not present for anyone. So Um, yeah, it just happens. But I would sometimes feel really, just, rushed, you know. This ‘we have to just try and get through this stuff and get back there. Oh! we have to get home. We really need to be there.’ And I probably spent like too much time thinking about that, and that was, I think that was what really built and built until I felt desperate at the end. You know it was like I just couldn't take all that pressure.
When able to bring their infants home, women identified a sense of relief from the intense experience they felt trapped in. Several women also described Personal despair magnifying their internal hopelessness, and inability to withstand the emotional distress they were enduring. Here, some women shared their thoughts about disappearing and suicide as a possible alternative to the pain of the NICU. Abby and Brooke articulated their experiences with this personal despair. Abby stated clearly “And I mean, there were times where I was suicidal. There were times where I’m like, I don't know if I can make it through this. I don't know if I can do this.” Brooke shared, “I needed to just kind of compartmentalize, to survive in those moments, because I feel like if I hadn’t done that, I would’ve curled up in a ball, and like not wanted to be a part of anything.”

**Escaping the Spiral**

The path to relief from the deep internal spiral women endured is defined by multiple avenues of supports and coping. Women engaged in these skills to help themselves escape the emotional depths of The Deep Dark Battle. The subcategories of this theme include: *Avoidance and Distraction, Family, Social and Online, Attuned Care, Counseling, Mom Pride, and Spiritual.* These subcategories are depicted in by the below image (see Figure 5). The image illustrates a spiral out of The Deep Dark Battle by using a multitude of strategies and supports. The repetition of these strategies is meant to outline that the strategies to escape the downward spiral are not meant to be used in any particular order. Not all of the women described finding support in all of the listed aspects. However, in each subcategory several participants spoke to the support they received from the aspect in order for it to emerge as a subcategory.
Avoidance and Distraction

This strategy engaged women in activities that helped them escape the distress of the NICU, including the use of social media, reading, and work. By being busy or distracting themselves, women found relief escaping the internal emotional experiences they were traversing.
Family

Women looked to their family for support. This support presented as both logistical and emotional. Though, in some cases, women were unable to rely on their family for emotional support. Some women reported experiencing care from family when they offered logistical help such as childcare for other children or help with managing schedules. One participant offered a clear example of how she received logistical help from her mother, but experienced the absence of emotional support.

Yeah. And then, my mom, she's... she's very supportive like she helped me out so much like cook, clean, do laundry. Take care of a baby, so I could sleep, you know, but at the same time she's (mom) not a very like emotional person (pause) how I am. So, whenever I would be crying or upset, and stuff, she would kind of just like, brush it off and say ‘you need to be grateful that they're okay.’ or ‘they're fine’. And ‘they're gonna be home soon. Just don't get upset’, and it's like don't tell me that. I need to feel the way I'm feeling.

Social and Online

Women sought social support outside of the NICU. Several of the participants found friendships and support groups online. Some made friends with other mothers in the NICU, despite strict COVID protocols preventing much opportunity for connection. Andrea used social media as a way to support herself. She described this as:

I did find myself reaching out to, and actually connecting with a lot of people...reaching out to people who, you know, I went to high school with or grew up with, or was a cheerleader, played soccer with, who had children in the NICU or were going through the same thing. I actually reconnected with a ton of people, who I otherwise wouldn't probably, you know, it's, you follow each other on social media...And reconnecting with a lot of people I probably otherwise wouldn't have.

Attuned Care

Participants discussed the ways they found support in care that was attuned to both themselves and their infants. When attuned care was present, women trusted the care by the medical team resulting in a more supportive environment. Attunement was described in several
ways. First, participants described instances when specific staff that connected to their needs.

Ellie expressed feeling connected to a specific neonatologist at her hospital.

It was nice because it she [Doctor], she was like, ‘I get it. I’ve been there.’ Like, ‘You did not fail him,’ you know. Of course, she reassured me about all of the things and um, you know pointed out all of the things he was doing well, he’s gonna get this, you know, like she just, it was a pep talk.

Women also described finding comfort and support when staff were particularly attentive to their infants. Jessie gave an example of finding support from attuned care. She stated,

But we did have like significant, like a couple [nurses], probably I'd say, maybe like two or three that were really supportive and kind, and just really good with him. I think that's what made it like easy for me.

Another aspect of Attuned care occurred when medical nurses and doctors were attentive to the relational health between the mother and the baby. Participants found support in staff offering ways for them to connect with their infant especially during times when they were not able to touch, hold, or care for their babies.

Counseling

Several participants described accessing mental health counseling as a support. They shared finding help in having someone to talk with and a place to share their emotional experiences. Several women in this study self-recognized their need for counseling and sought support on their own. Abby was able to identify her distress and need for mental health support early on in her NICU journey and reached out for help in her community. She described having thoughts of suicide during her experience in the NICU. Counseling offered her the mental health support she needed in order to navigate these intense thoughts on her emotional NICU experience. Similarly, Ellie described knowing she wanted counseling support during her pregnancy. She articulated the gratitude she felt for already having therapy in place when her son was placed in the NICU. She expressed finding relief and support in counseling.
Well, I (pause) I was really grateful that I was like already plugged into counseling like even during pregnancy. I had been going once a week. And thank God, because I’m too... I cannot imagine, like having to go through that again without having like my weekly counseling appointment. That, was just, you know, even if it was for an hour every week where I could just kind of talk about everything…. I don't know… counseling probably stands out as like the biggest [support].

**Mom Pride**

Women described placing energy recognizing the strengths of their infants, and expressed *pride* in their children’s fight, determination, and improvements. Women described finding hope and relief when they were able to focus their energy on these encouraging qualities. Women pulled on these exceptions of their infants as a way of support. Women held fast to this reorganization of their energy as they worked to escape the downward spiral they had been in. Mom pride served as a way women could help themselves. Jessie described her pride in her son and how she found strength and calm as she focused on him. She stated,

> They’d be like, ‘he's such an old soul,’ Because when he'd lay there he would just look at you and stare at you changing his diaper, never cried. He was just there, taking it all in. It just made everything so easy in the NICU.

**Spiritual**

Several of the women found comfort in *spiritual* experiences. For some women this was engaging in their spirituality which offered an opportunity to hold a broader perspective to something greater than themselves or their infant’s outcome. Brooke offered an example of how spirituality was supportive to her.

> I’m a very, very spiritual person. Um, I just think the biggest thing is just uh, just how blessed we are, you know. With all of the things that could have gone wrong, and all of the times that she really should have died, you know, I mean from the beginning her life. It wasn’t expected, and so, um, I just hold so tight to our faith, and knowing that, like she has a job on this earth, and she is here for a reason.

Others found ways to make meaning of their experience that offered a sense of hope and comfort for them to lean on. Jessie described a spiritual experience which brought her comfort.
Something like spiritual that happened for us while we, the day that I had gone, had, had delivered him. Um, we had on, like, you know, the board, and like the delivery rooms, and like they write the nurses names. Well, our nurse’s names were Kathleen and June, and those are both of our like myself and his [son’s] dad's, um maternal grandmother's names that have passed away. I’m like dead serious. And so they made their like presence like known…And so like in that moment, like I knew we were meant, not, you know, there was a reason why he was being brought to us, and so I think for me. Um! It was, I knew, like just that it was. This is how things were supposed to be.

**Post-Discharge – Integrating the Deep Dark Battle**

Women experienced post-discharge as a continuation of their NICU experience. Women reported high levels of anxiety post-discharge and were immersed in the work of integrating aspects of *The Deep Dark Battle*. Once home, some women began to explore and unpack their deep internal emotions of the NICU experience. Women identified aspects of the *post-discharge* experience as both challenging and wrought with emotional work. They also identified some personal reflections offering support to future NICU moms. Subcategories of this theme include

- **Post Discharge Trauma, Continuation of Guilt, Continued Medical Complications,**
- **Reflections of Pride, Longing for Understanding and Connection, Finding Meaning and Messages to Future NICU Moms.**

**Post Discharge Trauma**

Women hold fear for their infants well after being discharged from the NICU. This *post-discharge trauma* is where women began sifting through their trauma symptoms of hypervigilance and anxiety. For many of the women, post-discharge trauma was saturated with anxiety for their infant’s health and hypervigilance to prevent possible risk or harm to their infants. When asked about her experiences of the possibility of death for her son, Jessie shared her experience with this intense worry and need to monitor her son after discharging to home.

I think it was more so of like, you know, ensuring when we left (emphasized) the hospital. I think that's the only time [considered possibility of death]. Maybe, it was him having SIDS or something, because he was so tiny. And so, I was super cautious. I had
like one of those owlet monitors. And, yeah, just very aware, I think, after the fact versus like being in the NICU.

The anxiety that women experienced post-discharge, surfaced as constant worry about possible harm coming to their children. Women experienced fear of the risks associated with common childhood illnesses. They also experienced consistent worry of their infants facing breathing challenges, fears about dropping vitals and overall safety for their infants. Ellie highlighted these fears when she stated, “Because you know, it [anxiety] always changes. It’s like. Then they're eating solids. You're worried about choking. And they're mobile. It just is ever evolving. And it's exhausting to think like, ‘Oh, I'm never not going to be afraid.’”

Hypervigilance presented as women frequently checking their infant’s temperatures, watching home monitors for oxygen saturation and heart rates, and often assessing their infant’s environment in order to soothe their worry and keep their infants safe. Brooke offered an example of her hypervigilance.

I was still not sleeping in any capacity. I was constantly like ‘Is she breathing, is she?’ She had really bad reflux for like 3 months, especially with her feeding tube. And I would be like, ‘Is she going to throw up in the middle of the night? And I'm not going to be there to hear it? So, I would very literally sleep with my hand on her chest with her bassinet next to our bed.

Similarly, Ellie offered how her anxiety morphed into hypervigilance and checking behaviors with her infant. She magnified that even 14 months post-discharge she is still working through the trauma of her experience.

It's hard, and like all of a sudden. Then they talk about discharge, and then you go home. And where does that go [fear for child]? Right? Because that's still, it's still here. So, then it's turned into ‘Is he cold?’ I'm like checking his temperature all the time, just waiting for...Like ‘What's it going to be? Is he sick?’ And that was really hard too, to figure out what to do with, you know... And then I think it just kind of turned into some postpartum anxiety and depression. And, Yeah. Still navigating that 14 months later

Continuation of Guilt
Women also had experiences of ongoing guilt. Participants shared about guilt months following discharge, as continued to work through this experience. Ellie shared her journey through guilt post-discharge and leveraging antidotes of gratitude.

Something I will say is this: the guilt is the longest, hardest journey. One thing I want to talk about is how the guilt also turned to some inward hate for my body and how that's been tricky to work through. I think that the disconnect started when it became hard to get pregnant, and then hard to stay pregnant, and eventually the fact that we delivered early because I had preeclampsia. I can have moments where I am grateful for everything that my body was able to do to have [Tom], but for the most part I have felt very disconnected from my body and ashamed of all the ways it has "failed." I keep looking for a quick fix, but surprise- there isn't one!

Continued Medical Complications

Women described their experiences of infant’s continued medical challenges. For some, their children had high-risk and susceptibility to illness. For others attending to medical complications included the realization of longer-term challenges their infant may face.

Reflections of Pride

A part of women’s post-discharge experience focused on reflections of strength and perseverance when integrating meaning of their NICU experience. They described reflecting upon their own strength and their infants when surviving the NICU. Here women began to focus their energy away from their negative experiences and into the aspects of resiliency. Lindsay offers an example of pride for her infant and on her personal pride.

I just kept looking at him [son’s first birthday] and I was like, ‘Oh, my gosh! I can't believe that a year ago you were... you couldn't breathe on your own. You were like struggling to clock in at five pounds, and a feeding tube, and all of this’, and now he's kind of toddling around and yelling at me. So just I was really reflecting on that. And so, I think there's a feeling, you know, as far as like our narrative, that we kind of, you know, coming through that, on the other side [of NICU], and being... he's so strong now and he had this really rocky start. Now he's doing so great. And feeling kind of proud, I guess.

She described a similar feeling for herself too,
I mean, I guess I feel probably similar [proud of herself]. Like talking about that, my feeling [pride] as well. Kind of taking that on for myself, too. Like we had this hard start, and things were… things were really, really hard. But we came out on the other side… Then, kind of the way you just kind of integrate it into your story is like... like overcoming adversity. But when you look back and think on it, it is almost like a positive thing, because you're thinking about how you got through that [NICU adversity]. And so, you were strong.

**Longing for Understanding and Connection**

The Longing for Understanding and Connection emerged as an aspect of women’s post-discharge integration. This is where women found themselves wishing they had been met with understanding during their NICU stays. In this subcategory women shared about their deep desire to connect with others who understood their emotional experiences. Abby articulated the support she felt was lacking and the support she desired.

But, I feel like the social worker should have checked in daily. They should have came up there and said, ‘How are you doing? What do you need? How is your support at home?’ You know? ‘How are you feeling up here? Do you need more support while you're here? Do you need somebody to sit in here and hold a baby while you go to the shower?’ You know? ‘Do you need us to bring your meal up here for you?’ They would give me meal vouchers, and stuff sometimes, but that's only if they remembered. And then I felt guilty about asking.

Another participant described her desire to be understood. She described her experience of seeking emotional comfort from her husband.

Yeah, my husband, I don't think could, I think anyone who's a mom who's had a baby, I don't think, I mean, husbands sort of get it, but I don't think they really can understand how a mom feels.

She continued on,

And I think, you know, leaving your baby in the NICU for the first time and going home without them was probably the most traumatizing thing I've ever gone through. I mean, the car ride home was just bawling hysterically. And, um, and my husband's like, “You don't cry. I don't know how to even comfort you”. I'm not a crier, and so he's, he, I think just didn't know even how to comfort me. And it was I feel like it was really isolating because I didn't know anyone who had gone through the same thing as me, at that time.

**Finding Meaning**
During Post-Discharge women attempted to integrate and make meaning of their NICU experiences by advocating and offering care to others in similar circumstances. For some, this advocacy was in providing psychoeducation for other NICU women. For others, finding meaning meant attending to and creating opportunities to care to other NICU moms. Jessie offered an example about how she found meaning through offering psychoeducation to a relative.

I guess for me, I didn't really know [about NICU]. I think I said this before, I didn't know too much about the possibility of being in the NICU, and there wasn't a lot of psychoeducation around that. And so I had a cousin that just had a baby, and a lot of the conversation we had, was because she was very high risk, and they thought they were gonna have to deliver him at like 21 weeks to where... his chance of survival was minimal. But he ended up being able to go to 38, ...37 weeks. Yeah, and ended up healthy. But they had to do a NICU stay, and so, I think just having a different appreciation for just NICU moms. And then that whole process. But, I think just preparing my cousin like in talking with her was important.

A few of the women found meaning in re-storying their trying experiences in the NICU into stories of strength and survival. Brooke offers her narrative about how the emotional experience of the NICU has made her a better person.

this trauma with my daughter. And as horrifying as all of those things are, those experiences have made me a better person. So, even though I am obviously still emotional about so many things, and especially with my daughter, that experience [NICU journey] has made me a better person. It's helped me to see how necessary it is to be fully present with my kids. Because, I very easily could not have had that with her. It's made me a better mom. It's made me sometimes, most of the time, it makes me a better wife. Sometimes I get annoyed, but most of the time it's made me a better wife. I’m thankful that I’m to a place where I can acknowledge that those experiences that made me a better person, because I know, that there's a higher calling other than connecting with someone socially.

She continued by adding her ideas about advocacy for supporting other women enduring the NICU. She stated, “I feel really passionate about actually starting a group at [Hospital], and hopefully getting that rolling and making sure that that happens.”

**Messages to Future NICU Moms**
The final subcategory that emerged in the post-discharge experiences of NICU women is one of hope and encouragement. Here, women spoke not only what they wish for future NICU moms, but also to what they would have liked to know for their past selves as well. Women shared their messages, and lessons they hope others will hold as they navigate the NICU.

Women’s advice to moms: *Your Experience is Valid, Ask for Help, and Take Care of Yourself.*

Andrea summarized a message to other women on this journey:

> This is going to be the hardest thing you're probably ever going to go through as a mom. And it's gonna feel like the most traumatizing, horrible experience as you're going through it. But you know your baby is where they need to be to heal and to recover, and that you know you just have to trust the process... whether your baby is in the NICU for a day, or whether your baby is in the NICU for ten months, you know, I think, of course, the experiences are different, but I feel like, no matter what it's worth it to have your baby. You know they're where they need to be. And it feels like the most traumatizing part of your life, and it is. But you know, you get through it, and then there's nothing but like amazing fun experiences and then it's something of the past. It's not something that ever really goes away, but it kind of is something, it's just like another thing that happened. And it feels like, you know the days are sooo long and agonizing [in the NICU], but then it's like one day you wake up in a blink of an eye, and your baby is six months old, and they're accidentally rolling off the couch... Just sometimes things like that feels like time is going by so slow, but you're gonna wake up one day and say, ‘Oh, my gosh, my toddler's about to be two. How is this even possible?’ Yeah, so hang on. It could be a bumpy ride. But eventually, you know, you get to the end of it [NICU].

Jessie also offered encouragement to other mothers, “It takes a special kind of person to be a NICU Mom, and a certain type of strength. And even when you don't think you necessarily have the capability of being one. You do.” She went on further to offer, “Sometimes it's just as simple as taking it moment by moment, and reminding yourself that you're doing the best you can.”

**Summary**

The results of this study offer a scoping view of the experiences that women endure while having an infant in the NICU. The experience began with women describing their sudden entry into the NICU and navigating being overlooked. Women navigated this emotional process
WOMEN’S JOURNEY THROUGH THE NICU

with experiences and times of externalizing and distancing from their emotional experiences and then later experiencing a turn inward to process through their lonely emotional battle within themselves. As women began to understand the heaviness of the illness and possibility of babies dying, they began to struggle emotionally. Although many made attempts to compartmentalize their experiences, women ultimately moved internal to their own emotional process. The Deep Dark Battle is the core of women’s personal emotional experiences, filled with guilt, pressure, shame and personal despair. Women used supports to help themselves move away from this internal battle. After leaving the NICU, women experienced a continuation of many of the emotional aspects of the NICU, only without the medical intervention of the NICU. Post-discharge, women began to process their emotional experiences and integrate narratives of strength and resiliency.

The findings of this study provide insight about the pain and internal struggle women in the NICU are enduring alone. This information offers opportunity for medical providers and counselors to establish and refine mental health support and preventative care for women with infants in the NICU.
Chapter VI: Trustworthiness, Limitations, And Implications

This chapter reviews the trustworthiness, limitations, and implications of the phenomenology of women’s experience in the NICU, answering the research question: How do women with infants in NICU care make meaning of their NICU experience? I used Interpretative Phenomenological Analysis (Smith et al., 2009) to explore and give voice to six women’s experiences of this event through two, hour long interviews. Using the participants own words, constructed with my interpretations as the researcher, and created a co-constructed phenomenology of their experiences navigating the NICU. Despite effort to develop a trustworthy and rigorous study, limitations emerged. This chapter examines the steps taken to establish trustworthiness, presents limitations of the study, and addresses implications for medical care, counselors, counselor educators and for other NICU moms. Finally, considerations for future research are addressed and discussed.

Trustworthiness

Lincoln and Guba (1985) outline trustworthiness as the credibility and quality of a qualitative study. Particularly, trustworthiness is evaluated on credibility, dependability, confirmability, and transferability. There are many ways that trustworthiness is implemented throughout qualitative research. I used multiple strategies to establish trustworthiness in this study including prolonged engagement, member checking, implementation of Yardley’s Criteria (Yardley, 2000) (which is used in IPA methodology), reflexivity, and finally an inquiry audit.

Prolonged Engagement

Prolonged engagement was established by developing strong rapport and relationships with participants. I used empathy, reflective listening and openness as ways to develop trust. My own experience of having an infant in the NICU offered me an entry point to understanding the
culture and nature of the NICU setting the stage for authenticity, connection, and understanding with the women in this study. I offered women a brief disclosure about my own experience of having had my daughter in the NICU. Participants responded to this by relating and offering their detailed stories and experiences. Across the interviews women used language, shared details and even expected me to relate to data specific to the NICU culture and environment. By offering my disclosure a deeper level of trust and rapport was developed. At the same time, I made intentional effort before and after interviews to reflect on my experience and separate my experiences and thoughts out from that of the women I interviewed. I did this through journaling in order to identify and set aside my bias, thoughts, and own feelings. Prolonged engagement and strong relationships were important to this study as I asked deeply personal and difficult questions to gain a rich and thick description of women’s holistic and personal experiences of a deeply trying event in their lives. The depth of responses during interviews suggests strong relationship, trust, and prolonged engagement.

**Member Check Procedures**

I used member checks to establish credibility in my study. By offering participants the opportunity to review results, clarify their perspectives, and offer corrective feedback the data and interpretations were reviewed for accuracy. Formal member checks were conducted several weeks after the second-round interview data were analyzed and written as presented in Chapter Four. Final results were presented to participants in a visual diagram of themes (see Figure 2) the meanings they made of their NICU experiences. I shared the diagram with participants in an email prior to inviting them to participate in member checks via zoom. In member-checks I asked the following questions to help participants confirm, clarify, and correct the aspects of the analysis of their experience in the NICU.
1. Is there anything about the diagram or description that is especially resonating with you?

2. Is there anything I got wrong?

3. Is there anything that needs to be added?

4. Is there anything that needs to be changed or removed?

5. What are your overall impressions?

**Member Check Results**

Of the six participants in this study, three engaged in zoom meetings to discuss the results of the study. One participant, Ellie, who did not respond to the member check, articulated in her second interview that she had been dealing with heightened Postpartum Anxiety and Depression since taking her son home. She reported having counseling support to help her. The absence of response from Ellie regarding member checks may be due to this increasing energy she is focusing towards dealing with her NICU trauma and mental health. Using my diagram, I described the themes that emerged from the data. Women then engaged in sharing what resonated with their experiences. They also discussed aspects of the diagram that did not fit for them. Two of the women (Jessie and Lindsay) articulated that each of the themes and subcategories felt reflective of their experiences. Lindsay expressed her desire to see her personal experience of feeling torn between having a child at home and in the NICU be articulated more clearly. She offered a clear description in her member check about her thoughts on this. She shared,

one part is the division I felt of needing and wanting to be in the NICU and also needing and wanting to be home caring for my older son…. That is the only part that may not be totally represented in the image…. Doesn’t feel like the division of logistics and emotional in the Juggling act. I was so guilty for being somewhere and wanting to be another place. So torn. Maybe that can be articulated in the writing? How torn I felt. Like, I can’t have both of the things I want. And I feel bad about wanting both.
Jessie reported feeling that the model was accurate and appropriately captured her experience. She shared, “I like the meaning making part you provided. This whole thing resonates so well for me. All of it. I can find my own examples in each category.” At times, throughout the data, Jessie did not articulate her experiences with the same emotional depth as other participants. However, she reported in member checks resonating most with the theme of The Deep Dark Battle. This member check highlighted the way that other women were able to articulate her shared experiences in a meaningful way. She stated, “It’s really good. It’s hard to identify all of the pieces, but you did a nice job. I love the diagram. Specifically, I think you got it right with the Deep Dark Battle. That really resonated with me.” Lindsay also shared finding validation in seeing her experience in the image.

The Deep dark Battle through all of the layers is really important and accurate. I actually felt pretty emotional listening. I think I felt like you were talking about my interviews. I was surprised by how much it felt like my experience. It was totally validating. I also want to say that I feel like talking about my NICU experience, participating in this study, has been really great and good for my own process.

Andrea shared her thoughts that the model resonated with her overall. She focused on her experience of not having the personal care and support she felt she should have had.

The part that resonated the most for me is, it’s like your baby is getting 100% of the time and care and you are left as just the random shadow in the room. Not very often were people saying ‘are you okay?’

She also described her post-discharge experience as being validated by the data. There were Post-discharge parts that really stood out. “The reconnecting with others….and the anxiety. I’m still psychotically checking the monitors. And I think it’s just the PTSD, and I wonder if that could have been different.”

She then returned to this:
There is just not enough support for moms at all. During your pregnancy you see your doctor a dozen times. Postpartum moms see them twice. Why isn’t there a therapist on site. And you don’t have to access them and I can’t imagine a mom not being okay with a therapist coming in saying how are you doing today, are you okay? Can I get you something to eat? Do you want to talk?

Three of the participants were unable to meet for zoom member checks. Instead, I sent the diagram with detailed descriptions of each theme and overviews of the subcategories within each theme (See Appendix J). I did not receive feedback from the 3 participants who were sent results via email, and invited to meet.

Overall, women identified finding deep resonation with the results of the study. One Participant expressed her experience of being torn between two places at once, in her case, between children, as prevalent. She wanted to ensure this was noted as an emotional aspect she had to navigate. This experience emerged in women’s experiences of guilt, and more data was added from several women in order to clearly mark this part of the phenomena. Women described finding their stories in the interpretations and results of the study. They also described the results as meaningful and accurate to the meaning they made of their time in the NICU. The results of the member check were a powerful tool for me in ensuring that I analyzed the data in a way that was accurate to participants experiences. It was important and powerful to see and hear women identify themselves, and their experiences in the results. The articulation by women for other women in the study, particularly for those who may not have been able to access the depth and language of the experience, offered powerful insight and meaning-making.

**Yardley’s Criteria**

Yardley’s Criteria (Yardley, 2000) is a set of practices used within IPA methodology that supports the establishment of validity. This study used sensitivity to context, commitment and rigor, transparency and coherence, and impact as a way to establish trustworthiness.

**Sensitivity to Context**
Due to personal experience, my awareness of the environment and culture of the NICU allowed me to enter conversation and connection with participants with sensitivity. I used sensitivity when considering the inclusion criteria of 6-18 months post-discharge, as it was necessary and important to allow women to adjust to their roles at home post-discharge. I was attuned and sensitive to technical language participants used regarding their infant’s medical experiences, and their descriptions of their own experiences. I used empathy and sensitivity in development and timing of interview questions, knowing that the difficulties women faced varied, could be painful, and held emotional depth. I remained open and empathetic as participants shared their experiences, and also did so throughout analysis in the development of the phenomenology. I used participant language to inform codes, themes, subcategories and properties during data analysis. I remained in-tune to the details during data analysis and gave thought and effort when extracting and placing data to support themes. Attention to the sensitivity of context adds trustworthiness to my study by using the data to accurately portray the participants’ stories and meaning they make of being a woman while having an infant in the NICU.

**Commitment and Rigor**

During recruitment, data collection, data analysis and the member checks, I was intentional with the care and attention I input to the study. I was deliberate in my selection of participants to ensure that the data speaks to the group I identified (parental status, partner status and race). I gave extensive focus to details from my interviews with participants. I transcribed interviews increasing my engagement with the data. I conducted three layers of initial coding for each transcript from each interview in order to assure that I was accurately portraying the data. I used multiple interviews to ensure that the data supported themes across participants and
interviews. I conducted my analysis thoughtfully, with a large time investment to each round of interviews and attention to detail.

**Transparency and Coherence**

Throughout the study I remained transparent about participant selection, the interview process, and methods and results of data analysis. My inquiry auditor, Dr. Kirsten Murray, and I met weekly where I explored my personal reflexive experiences, discussing and addressing personal bias, and working to make sure that interpretations were aligned and accurate with what participants were describing. She invited me to examine raw data, and I was transparent with the challenges I faced. I asked for, and remained open to feedback from my inquiry auditor, ensuring that I remained in-tune and accurate to the data. Throughout the study I was open and transparent with participants about the aim of the study and about what themes were emerging. I offered participants opportunity to ask questions and share their thoughts and feedback in both rounds of interviews and member checks.

**Impact and Importance**

This research provides valuable, important, and useful information for women who have an infant in the NICU, their providers, and their counselors. The results offer a guide about participants’ personal experiences and highlights ways to care for the women who encounter this significant event in a way yet to be described in the research. This impact and importance indicates the validity of the study and rigor with which the research was conducted.

**Reflexivity**

Throughout my study I used reflexive journaling as a way to keep my personal experiences and biases in my awareness and reground in participant voices and experiences. I engaged in journaling before and after interviews, as well as after my meetings with my inquiry
This practice supported being able to sift through my thinking and put aside parts of my personal thoughts and feelings in order to accurately capture the points and messages that the women were offering in the data they provided.

Through reflexive journaling I was able to identify areas of the data where possible bias, or my own experiences could inform the data analysis. When this occurred, I had the opportunity to explore with myself and my inquiry auditor how to move away from my own assumptions and reground with participants and the data they offered. One example of this was surrounding the topic of body failure. As women described their sense of their body letting them down, it was personally familiar to me. I reflected that my term for it from my own experience was ‘body betrayal’. Although this concept surfaced in the data from all of the women, I reflected and invited feedback and further exploration from my inquiry auditor to check that I was removing my own bias and experience from what the data revealed. With this reflection I was able to put their language to the experience rather than use labels from my personal experience. The data suggested they felt failure, and that their body was the failed vessel.

Another way that reflexive journaling ensured participants’ voices were in the forefront of the analysis was with regards to how they expressed their experience with bypass of themselves. As women shared about experiences in which they desired personal care and mental health support to be more present, it was easy for me to become passionate about women being overlooked. My bias began to inform the titles of subcategories to be more direct and pointed. With reflexive journaling and support from my inquiry auditor and chair, I was again able to become aware of my bias and remove my emotion from the analysis. Women, although disappointed with the lack of support from the system around them, were not so direct with their language. By revisiting the data I was able to reach the theme of The Forgotten Mother.
practice of reflexive journaling supported my continuation of grounding in the participants’ experiences and increased accuracy of the results of the study.

Inquiry Audit

The inquiry audit was used to ensure my study was done with rigor and consistency that the data in fact, was congruent with my interpretations. Weekly meetings with my inquiry auditor were used to review data and supported the development of themes, subcategories, and properties established from the data. The meetings discussed reflexive practices and reflected on my personal bias and experiences in order to ensure that I stayed in alignment with the data with my interpretations accurately represented the voices of the participants.

In conclusion, the methods of prolonged engagement, member-checking, rich descriptions, the use of Yardley’s criteria (including, sensitivity to context, commitment and rigor, transparency and coherence and impact and importance), and the use of an inquiry audit helped establish trustworthiness of my study.

Limitations

Several limitations emerged from this study. The most prominent limitation is the homogeneity of my sample. I desired and attempted to have variation within the sample in order to capture variation of the population, however there were several aspects of variation that I was unable to acquire in the participant pool. I intended to recruit at least one participant that fell below the poverty income threshold in order to capture variations of experiences from her. Despite my efforts, all of the participants reported being above poverty income thresholds. All of the women had more resources to pull from, especially financially, that possibly buoyed them in a different way than women in poverty. As a result, the experiences of women below the poverty threshold were not represented. Women encountering poverty while also navigating the
NICU may have varied experiences based on the amount of resources and supports accessible to them.

This study focused on the experience of women with healthy infants 6-18 months post-discharge. The women in my study were not navigating chronic illnesses or managing long-term diagnoses for their infants. It is likely the experiences of the NICU may vary for women who have to navigate intensive levels of care for their children.

While this study is oriented to the Northwest, four of the participants were from Montana and two were from Oregon. There was not representation from Washington or Idaho and two states in the Northwest were represented in this study.

In addition, there was one person of color in this study, so the dominate voices continued to be of white women. This is an important consideration as it leaves room for further representation in future research. None of the participants in this study were black. This is a critical consideration, as the birthing experiences for black women remain explicitly more dangerous in the United States: regardless of income level, black women and their infants have higher preterm complications than white women (Kennedy-Moulton et al., 2022). The preterm birth rate among black women is 52% higher than rates of all other women (National Center for Health Statistics [NCHS], 2021). For black women, birthing in the U.S. carries significant risk factors that could influence their experiences of the NICU. All of the participants in this study were women that had their children before ROE V. WADE (Roe v. Wade, 1973) was being appealed by the supreme court. This means that all of the women in the study chose to carry their infants to term. This study does not include the voices of women who are navigating forced pregnancy and motherhood. Nor does it reflect a NICU context of increased demands for infant care as the population increases. Finally, this study does not capture medical providers
integrating legal consequences of abortion, or what may be considered abortion, into their medical decision making on behalf of the women they serve.

The timing of this study was such that the women interviewed for this study all had infants in the NICU during the COVID pandemic. Women discussed their perceptions of being isolated due to COVID, at times unable to distinguish between the hospital protocols in place before the pandemic occurred. The pandemic created barriers for women to have the support system they desired during birth, and limited visitors to the NICU. Although there were tighter restrictions in place due to COVID, it is unclear as to how this played into the experience of isolation. It is common practice of NICU’s to limit visitation by others, beyond the parents, during the months of heightened illness. Women described being alone and isolated, unable to access mothers in other NICU rooms. This is a protocol often in place despite the COVID pandemic. More prominently, COVID created systemic challenges that hospitals faced during this time (WHO, 2020). Staff shortages were prevalent, and led to difficulty for patients and the system alike. The strain on the system during COVID produced gaps in care, and infrastructure collapse (WHO, 2020) that possibly magnified women’s experiences in the NICU. For these reasons COVID must be considered when discussing transferability of this study.

Another limitation of this study is the response rate to member checks. Though the responses received were confirming, three of six participants engaged in zoom member checks. Half of the participant could neither confirm, deny, or provide additional insights to the final results.

**Implications**

This study captured the personal experiences of women navigating the NICU after delivering their infant(s). The personal experiences women articulated offer valuable information
to other NICU women, hospital staff, providers, counselors, and counselor educators. More specifically, this study highlighted women’s experiences of deep internal emotional struggles and loneliness as they endured the challenges of being in the NICU. Women offered insight about their need to have increased emotional, physical, and mental support. With this clarity and depth, many spaces and professions can take note of adjustments to re-design and increase support and care for NICU women.

**Medical Care**

As Family Centered Care (FCC) and Newborn Individualized Developmental Care and Assessment Program (NIDCAP) become the focused approach to practice, this study offers information about the continued need to address women and their personal needs as they navigate the NICU with their infants. In these environments, providers are stretched in many directions and are appropriately prioritizing the life and wellness of the infant. And, women experienced a decreased capacity of medical staff working with the entirety of the family system, and the mothers in particular. Although the women in this study offered understanding for the many demands placed on medical staff, there were no readily available routes of support for the women to receive regular check-ins, support, and at times welcomed integration for providing care and connection to their infant. Providers can consider adjustments to offer brief check-ins and even aim to offer care.

As women experience heightened symptoms of anxiety, depression, and navigate their internal emotional experiences, accessing counseling while having their infant in the NICU may be a luxury that women are unable to engage in. Medical systems can address this barrier, by having a clinically trained counselor on staff who is present during rounds, and is easily accessible in the NICU setting. By rounding with the physicians, women will become
acquainted with the clinician, moving beyond the frequent barrier of meeting and getting familiar with a counselor. With mental health counselors built into the medical system there is possibility of eliminating the barrier of the woman needing to seek out her own support. With opportunity for familiarity, access, and rapport building, engaging in mental health counseling may be more easily accessible and used. This counseling support during women’s NICU stay can help in their heightened emotional journey, but also may act as a bridge and referral system for women as they leave the NICU and return home. This study highlighted the need for continued mental health support after women left the hospital, as they were still carrying and facing their own emotional experiences of being in the NICU.

This study also offers information to Nurses, as the frontline, about effective practices for supporting women as they navigate the NICU. Results indicated that women felt cared for when the nursing staff offered opportunities for mothers to engage in their maternal role. When attention was given to the relational health between mother and baby, women felt more supported and seen. By offering opportunities for women to be hands on with their infant, the struggle women faced softened. Nurses can support women by continuing to create memorable moments with their infants such as bath time, celebrating special moments and holidays, and helping women notice and mark successes. Similarly, nurses should consider the direct and indirect ways that they may overlook the mother’s care and begin to shift towards offering moments of connection. Nurses can attend to the orientation of the women to the environment, and support opportunities for her own hygiene and personal care, while not taking opportunities to care for her infant away. Finally, the ways in which medical staff, nurses and doctors, and other providers communicate with women has a direct impact on women’s experiences in the NICU. Hospital staff can aim to understand that women are in a deep emotional struggle, despite
how their emotional expression looks, and work to use soft, kind, clear communication with women as they move through the NICU. However, staff may not be clinically trained to skillfully address the emotional turmoil and distress the women in this study described enduring. This study highlighted and clarified women’s need to have counseling support while in the NICU.

The infrastructure of medical systems may also be addressed and adjusted to further support women in their experiences. Medical systems may offer orientation to the NICU in such that women would have access and knowledge about showers, laundry options, and food in order to address their personal care needs. As women spend their days in the NICU, accessibility and ease to food and water may be offered in a nearby lounge setting. Adjustments to proximity between NICU and Labor and Delivery, could be addressed in order to eliminate struggles for women to gain access to their infants in days immediately following the birth of their infant. Finally, women experience open bay rooms as distressing due to the small space, overstimulation of sensory input, and emotionally saturating dialogues around them. The awareness from this study offers opportunity for medical systems to begin addressing possible ways to ease the emotional strain on women, who are sometimes spending 12-hour days in a small, overstimulating space, immediately postpartum.

FCC ascribes to treating all of the individuals within the family of the patient. This study informs about the possible need for NICUs to implement surveys and feedback loops about what women are experiencing in various intervals throughout their stay, to examine and understand more clearly how women are doing mentally and emotionally. Feedback from the women may offer information about how to further support women in this setting. As women leave the hospital supports, their internal fear and trauma remains and continues to be a part of women’s
struggles. This study also lends to the need for early intervention of follow-up care for women after their infant is discharged from the NICU.

Although many NICU’s aim to offer consultation and education to mothers who they know will have an infant placed in the NICU, it is often an unexpected event, leaving little time for consultation and education to occur. Instead, NICU education can be integrated into childbirth preparatory classes, offering opportunity to normalize and orient to the basic concepts of the NICU. With such a high percentage of births ending in the NICU it could be supportive to women to offer early information about the topic. This may better prepare women for the experiences they could possibly face should they have an infant placed in the NICU.

Counseling

Ten percent of mothers have an infant placed in the NICU. Nearly 30% of women in the NICU experience PPA, PPD and suicidality (Beck, 2003; Lefkowitz et al., 2010; Lotterman et al., 2019). With these heightened rates the likelihood of mental health providers and counselors supporting a woman who has been in the NICU is great. This study provides opportunity for counselors to better understand the NICU experience for women they may be working with. Themes of external pressure, internal guilt, shame, emotional distress during and post-discharge, and a deep longing to be understood and emotionally supported, counselors have an opportunity to advocate with the medical system to increase support to this population. While hospital social workers often link NICU women with instrumental medical support and resources, women in this study described a lack of emotional and mental health support from this role in the NICU. This study offers insight that women are entering these deep dark places alone and without necessary support. Women in the NICU, postpartum women, should have access to Mental Health Support that offers a continual, accessible, predictable weekly and hourly times for
women to seek counseling care. Counseling provides places for women to enter the Deep Dark Battle alongside someone who is trained with supportive interventions. By offering this mental health support it may serve as preventative care for severe postpartum depression, anxiety, PTSD, and suicidality as the experience of these NICU women provide clarity about experiences encountered before entering into these diagnoses. Again, counseling support may be integrated into NICU care, using FCC by bringing the counselor to the woman. This may be done by providing a clinically trained counselor on staff who is present during rounds, and accessible to women for counseling sessions while she has an infant in the NICU setting.

**Post-discharge Care**

This study also offers clinicians working within maternal health, an opportunity to begin to foresee possible barriers and challenges for women navigating the NICU. It also provides insight for clinicians working with women who are post-discharge and are beginning to sift through their experiences. With an understanding of what women may possibly experiencing, counselors can offer education and validation to women. They may also be able to hold an understanding of possible emotional experiences in order to help women articulate and process their experiences.

The women in this study described their post-discharge experiences as an important time. During the post-discharge experience women reported beginning to wade through all that their event in the NICU held for them. Women in this study articulated using compartmentalization as a skill for survival. After the NICU experience was over, women are finding themselves in the depths of anxiety, PTSD symptoms, and symptoms of depression. They also described continuing to work through their guilt, shame, and the saturating experience of watching their infants and infants around them suffer. These women described needing help to unpack and
integrate the remaining pieces of their experiences. Although, the women and infants of this study have returned home, they are continuing to work through the negative consequences of their time in the NICU. Even during interviews, as far as 18 months post discharge, I was confirming that women were receiving counseling support, as they continued to identify emotionally struggling due to their experiences in the NICU. Women continued to exhibit symptoms of PTSD, anxiety, and depression at this distance from their experiences. Again, the study offers insight about possible challenges that women post-discharge from the NICU may be working through.

As counselors work with women post-discharge from the NICU, this phenomenology offers them perspective to the varied emotional states that women in the NICU face. The results of this study revealed how women’s emotional process moved from points of external focus to internal focus, and then back out again. In the Juggling Act women placed energy and focus on doing rather than feeling, and although they may be having deep internal struggles, their outward expression and demeanor may appear otherwise. During the Deep Dark Battle women turned inward with their emotions. Women varied in their expression and vocalization of this time, though all reported their experiences with it. The emotional state that women are in during their NICU stay and post-discharge may or may not be explicit. In this way, counselors may think that women are managing and doing well when in fact this phenomenology offers us information that they may simply be focusing their emotional energy in a variety of ways and expressions. For example, women could be intensely juggling tasks, appearing focused and busy, and still be suicidal. The results of this phenomenology offer opportunities for counselors and providers to address two important topics that are often socially taboo. The phenomenology recognizes and names women’s fear and worry about dying infants and the magnitude of pain they feel from
this. Counselors can invite women to speak about their fear and experience with the 
pervasiveness of death they must navigate while having an infant in the NICU. Secondly, this 
phenomenology names the reality that a high percentage (30%) of women in the NICU 
experience such suffering that they have suicidal thinking (Beck, 2003; Lefkowitz et al., 2010). 
Counselors working with women post-discharge can offer supportive risk assessments in order to 
understand risk of suicidality and levels of depression and anxiety that women are working 
through.

Similarly, women may be reaching out to health departments, physicians, and lactation 
consultants, after discharge, as they care for their infant’s needs. Clinics supporting women and 
babies, can use information from this study to have a deeper understanding of the possible 
experiences that women are navigating. This understanding may be used to further support by 
offering women validation of aspects their experiences and by providing resources such a NICU 
mom’s groups and counseling recommendations and referrals.

Psychoeducation and Prevention

On a larger scale, the NICU is something that needs to become normalized. Ten percent 
of pregnancies will enter into the NICU (NCHS, 2021). With the recent overturn of Roe vs. 
Wade, it is likely for this number to increase. With this information, there is pressure to begin 
informing and teaching about the NICU in public health arenas in order to prepare pregnant 
women and their families for this possibility.

This study offers insight about how psychoeducation may be used in doctor’s offices in 
order to teach women about the possibility of the NICU. For high-risk mothers, early orientation 
to the NICU and references to mental health support could serve as ways to increase care. This 
preventative teaching could possibly preempt some of the feelings of surprise, fear, and
uncertainty when women’s infants are unexpectedly admitted to the NICU. It may also offer opportunity to address and decrease the magnitude of grief that women will experience as they move through lost moments and dreams with their newborn. Finally, it could offer orientation to the medical system, environment and support adjustment to the women’s new role as a NICU mom.

**Counselor Education**

The results of this study call for more education focused on maternal health in counselor education training programs. Counseling Education programs have the opportunity to integrate maternal mental health as a special and relevant topic. In the last year, 384,000 infants and their families in the U.S. entered into care of the NICU (NCHS, 2021). For NICU mothers rates of mental health outcomes are vastly greater for NICU mothers than mothers with healthy term infants (Lasiuk et al., 2013; Lefkowitz, Baxt & Evans, 2010). These higher rates also occur for months after post-discharge (Hynan, Mounts, & Vanderbilt, 2013; Lefkowitz e al., 2010; Lotterman et al., 2019). The likelihood that counselors will work with women who have faced the experience of the NICU is high. If counselor educators offer training around maternal mental health, specifically addressing women in the NICU, the clinician has the opportunity to be prepared and skillful in their support to this population. Understanding women’s internal experiences after having an infant in the NICU also supports overall health of the family system. As well, it increases wellness of other systems the woman may be involved in, such as social systems, and systems of her workplace. Counselor educators can build training about this population, and phenomenology, into classes that provide holistic approaches to understanding the social, cognitive, physiological, and emotional changes that people and systems move
Classes such as Developmental Lifespan, Couples and Families, and Mental Health Systems may support curriculum that addresses this form of attuned care for NICU women.

**Children and Families**

Maternal mental health can have lasting impacts on family relationships and on child development (WHO, 2022). Maternal PPA and PPD can have both short and long-term consequences to children’s health and development physiologically, emotionally and behaviorally (Ainsworth, 1979; Field, 2010). Similarly, attachment and bonding can be disrupted between mother and child when women are struggling with mental health challenges (Ainsworth, 1979; Field et al., 2006). With some understanding of what women may experience in the NICU, and the high rates of PPA, PPD, and suicidality in this population, there is opportunity for intervention. With interventions such as orientation, education, and counseling during and post-discharge of the NICU, there can be better support for children and families.

**NICU Women**

Finally, this study offers insight from women to women who are also on this journey. It offers validation to the NICU mother, attempting to navigate sudden losses, unexpected and often unwelcome changes in their birth, and first days with their infants that are not only unfamiliar but cloaked in worry, concern, and fear. The results of this study offer understanding and validation of the juggling of logistics and mental emotional barriers NICU mothers manage. The results also offer validation to women encountering internal emotional battles. This study brings awareness to the emotional journey that women are enduring as they simultaneously negotiate their own wellness and mothering their NICU infant.

Universality of this experience can support women to realize that their challenges and emotional experiences are not unique to only them. This shared experience offers women the
opportunity to not feel so alone in their experience, and may lessen the magnitude of their isolation and silent struggles. As women navigate away from isolation they can find satisfaction in connection with understanding others, which may offer them hope. The information from this phenomenology may also offer a guide about the possible experiences, providing women predictability and opportunities to seek preventative care for themselves.

**Future Research**

The current study highlights the holistic experiences of women with infants in the NICU. The study offers insight about the meaning they made of their experiences. Despite thick and rich descriptions of this experience, there is more research to be done to continue to gain understanding and develop effective interventions and supports for NICU women. There is value in examining different factors present for women which may add differing attitudes and beliefs to this experience. For example, all of the women in this study chose to carry their infants. With changing laws, there will be future NICU women who may not have desired to carry their infant to birth, and are still faced with the difficulties of the NICU. Gaining understanding of this populations’ experience could add insight to how women navigate this journey. All of the women in this study also had infants without long-term health complications at discharge. Other factors to consider when gaining understanding about women’s attitudes and beliefs of this experience include, examining the experiences of women whose infants are living with long-term diagnoses. Another population to explore the experience with would be women whose infants have died while in the NICU. This study, captured the majority voice of women with partners. Although maximum variation was met regarding this criterion, only two participants were navigating having an infant in the NICU while being a single mom. Future research should examine single moms’ experiences while having an infant in the NICU. Due to
increased demands on resources such as time, energy, and possibly, financially, the experience for single moms is likely different. Finally, factors such as poverty and race may deeply influence the experience of being in the NICU and should be further explored. These variations in participants may offer an even richer understanding of this experience for women.

Similarly, one of the limitations of this study was the lack of heterogeneity in the sample. Future research could further explore how women who hold minority identities experience the NICU. In particular, gaining insight about minority populations such as black women with NICU infants, who experience a disparity in maternal care when compared to all other women (NCHS, 2021), would be important as women in the NICU are given voice. Further, future research should explore and gain a deeper understanding of participants with intersecting identities and their experiences while having an infant in the NICU.

Future research may explore the holistic experiences and meaning made by fathers and partners of NICU infants. Past quantitative research suggests that the mental health outcomes of fathers differ from that of the mothers (Fegran et al., 2008; Lefkowitz et al, 2010). This study offered brief insights about women’s partners and the ways that their time and time prioritization differed from that of the mothers. Due to varying factors including roles, time spent, and differing pressures it could be helpful to gather a deeper understanding of partners experiences with having an infant in the NICU.

The results of this study also suggest opportunity for further quantitative research. Researchers may use this phenomenology to inform development of a survey about women’s health and wellness postpartum in the NICU. For a quantitative follow-up study a factor analysis could be run based on women’s reports from this study and results of the survey to see if there are correlations between the survey and other measures of depression, anxiety and suicidality.
This further research may be supportive in developing measures to attend to the warning signs of women’s mental health.

Another area for future research includes detailed examinations of specific aspects of themes from this phenomenology. This may support greater depth and understanding of where women were most severely impacted along their NICU journey. For example, in the theme The Forgotten Mother, a survey could be developed to gain insight about women’s experiences with personal care, and experiences of being bypassed. The medical system may then begin to receive feedback about women’s experiences in the NICU and quantitative studies may be developed to study the implementation of FCC.

**Summary**

Having a newborn admitted to the NICU is inherently stressful and anxiety provoking for the mothers of these infants. In this study six women described their personal journeys through their infants’ NICU stay. Women described navigating sudden and unexpected entry into the NICU. They endured the loss of dreams about their first moments and days with their infants. Women articulated the grief they held surrounding their inability to hold or connect with their newborn infants. Women described feeling overlooked and forgotten in their personal care as a woman and as a mother. Throughout this study women highlighted managing juggling tasks, both logistical, mental and emotional loads they had to manage. These tasks, though challenging, offered an external focus to help women remain focused on doing and staying present in the NICU. Eventually, women discussed entering a downward internal spiral where they had to navigate their own suffering and emotions activated in the NICU. Some of these feelings included guilt, pressure about being a good mom, shame, and personal despair. Fortunately, women also reported finding supports along the way. After discharge women told of their
journeys sifting through their Deep Dark Battles and integrating all that had occurred for them during their NICU stays. Women discussed experiences with continued fear for their infants. They also were left with trauma and deep emotional strain as they integrated these difficult experiences into their lives and narratives. In the end, they were able to reflect and offer encouragement and hope to future mothers about what may have made their experiences a little bit easier.
Appendix A
University of Montana IRB Approval

INSTITUTIONAL REVIEW BOARD
for the Protection of Human Subjects in Research
FWA 00000078
Research & Creative Scholarship
Interdisciplinary Science Building 104
University of Montana
Missoula, MT 59812
Phone: 406-243-6672

Date: August 12, 2022

To: Molly Murphy, Counseling
    Dr. Kirsten Murray, Counseling

From: Paula A. Baker, IRB Chair and Manager

RE: IRB #132-22: “Women’s Experience Having an Infant in the NICU”

Your IRB proposal cited above has been APPROVED under expedited review by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 110. Expedited approval refers to research activities that (1) present no more than minimal risk to human subjects, and (2) fit within the following category for expedited review as authorized by 45 CFR 46.110 and 21 CFR 56.110:

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

All consent forms used for this project must bear the dated and signed IRB stamp. Use the PDFs sent with this approval notice as “masters” from which to make copies for the subjects.

There is no expiration date on this approval (per revised federal regulations effective 1/21/2019). However, you are required to notify the IRB of the following:

Amendments: Any changes to the approved protocol, including the addition of any new research team members, must be reviewed and approved by the IRB before being made. Amendment requests must be submitted using Form RA-110.

Unanticipated or Adverse Events: You are required to timely notify the IRB if any unanticipated or adverse events occur during the study, if you experience an increased risk to the participants, or if you have participants withdraw or register complaints about the study. Use Form RA-111.

Human Subjects Protection Training: As the Principal Investigator(s), it is your responsibility to ensure that the training certificates of all research team members are current (within 3 years) throughout the duration of the project.

This approval only applies to this specific project and may not be extended to any other projects, no matter how similar. Separate IRB applications must be submitted for each separate project.

Please contact the IRB office with any questions at (406) 243-6672 or email irb@umontana.edu.
SUBJECT INFORMATION AND INFORMED CONSENT

Study Title: Women’s Experience with having an infant in the NICU

Investigator(s):
  Doctoral Student: Molly Murphy, MA, LCPC
  Department of Counseling at the University of Montana
  Molly2.murphy@umontana.edu
  406-370-6696

  Faculty Supervisor: Kirsten Murray, Ph.D.
  Department of Counseling at the University of Montana
  Kirsten.murray@umontana.edu
  (724) 910-1905

Inclusion Criteria:
Participants in this study will be:
  • Birth giving mothers of infants in the NICU
  • Have infants who are healthy
  • 6-18 months post-discharge from the NICU

Purpose:
The purpose of this research study is to examine and learn about the holistic experience of women while they navigate having an infant in the NICU. This study will highlight women’s experiences and meaning making of having an infant in the NICU. The results of this study will provide information in this important area, offering medical providers and counselors information as they strive to better understand and support NICU Mothers.

Procedures:
If you agree to take part in this research study, you will be asked to participate in an interview about your experiences as a woman who had an infant in the NICU. The study will require participation in two interviews lasting approximately one hour each. Your initials indicate your permission to record the interview. Interview recordings will be encrypted and stored on a password-protected hard drive, and later transcribed. Identifying information will be removed from the transcription. After reviewing the transcripts for analysis, I will request your feedback about the initial results to ensure that I have accurately captured your experiences.

Risks/Discomforts:
You may experience emotional discomfort as a result of recalling difficult experiences when participating in this study. You have the right to stop the interview at any time and for any reason without consequence. Appropriate counseling referrals will be provided to participants if difficult emotions arise, and you wish to seek professional assistance.
Benefits:
Your participation in this study will further inform medical providers and mental health counselors about the experiences of women who have an infant in the NICU. It will help identify areas for future research. There is no guarantee that you will receive any benefit from taking part in this study.

Confidentiality:
- Your records will be kept confidential and will not be released without your consent except as required by law.
- Your identity will be kept private.
- If the results of this study are written in an academic journal or presented at a professional meeting, your name will not be used.
- The interview recording will be transcribed and identifying information will be removed. Data will be destroyed after 7 years. Pseudonyms will be used and linked to the interview transcripts to protect confidentiality. Data will be stored on secure password protected servers. Your signed consent form will be stored in a file separate from the data.

Voluntary Participation/Withdrawal:
Your participation in this research study is entirely voluntary. You may refuse to take part in or you may withdraw from the study for any reason at any time without consequence.

Future Research:
Identifiers might be removed from the identifiable private information and could then be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you or your legally authorized representative.

Questions:
If you have any questions about the research now or during the study, please contact Molly Murphy at (406) 370-6696 or molly2.murphy@umontana.edu, Kirsten Murray, Ph.D., the supervising professor, can be reached at (406) 243-2650 or kirsten.murray@mso.umt.edu. If you have any questions regarding your rights as a research subject, you may contact the University of Montana Institutional Review Board (IRB) at (406) 243-6672.

Statement of Your Consent:
I have read the above description of this research study. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will also be answered by a member of the research team. I voluntarily agree to take part in this study. I understand I will receive a copy of this consent form.

Printed Name of Subject

Subject's Signature Date

The University of Montana IRB
Expiration Date
Date Approved
Chair/Admin
Appendix B

IRB Amendment

Form RA-110  (Rev. 08/18)

THE UNIVERSITY OF MONTANA-MISSOULA
Institutional Review Board (IRB)
For the Protection of Human Subjects in Research
AMENDMENT REQUEST

Please provide
IRB Protocol No.: 132-22

Email this request as a Word document to IRB@umontana.edu, or provide a hardcopy to the IRB office in the Interdisciplinary Science Building, room 104. NOTE: Submission of this form from a University email account constitutes an individual’s signature; students submitting electronically must copy their faculty supervisors.

<table>
<thead>
<tr>
<th>Project Title: Women’s Experience Having an Infant in the NICU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal Investigator: Molly Murphy</td>
</tr>
<tr>
<td>Title: Doctoral Student</td>
</tr>
<tr>
<td>Signature:</td>
</tr>
<tr>
<td>Email address: <a href="mailto:molly2.murphy@umontana.edu">molly2.murphy@umontana.edu</a></td>
</tr>
<tr>
<td>Work Phone: 406-370-6696</td>
</tr>
<tr>
<td>Department: Counseling</td>
</tr>
<tr>
<td>Office location: Phyllisy J, Washington College of Education and Human Sciences</td>
</tr>
<tr>
<td>Faculty Supervisor (if student project): Kirsten Murray</td>
</tr>
<tr>
<td>Department: Counseling</td>
</tr>
<tr>
<td>Work Phone:</td>
</tr>
<tr>
<td>Signature:</td>
</tr>
<tr>
<td>Email: <a href="mailto:kirsten.murray@ms.umontana.edu">kirsten.murray@ms.umontana.edu</a></td>
</tr>
</tbody>
</table>

Detail the proposed amendment (protocol, recruitment, confidentiality plan) below and attach any consent/assent/permission forms for IRB approval (if possible, use Office’s “track changes” feature in your attachments):

I am applying to amend my inclusion criteria and the recruitment process for this study. The proposed amendments include:

1. Increasing the inclusion criteria from 6-12 months post-discharge to 6-18 months post-discharge from the NICU.

   Inclusion Criteria:
   Participants in this study will be:
   - Birth giving mothers of infants in the NICU
   - Have infants who are healthy
   - 6-18 months post-discharge from the NICU

2. An additional line at the end of the interview protocol to read: If you know of anybody else that might be interested in talking to me please pass my email information (molly2.murphy@umontana.edu) along to them.

Attached you will find the updated interview protocol and informed consent with amended inclusion criteria.

IRB Determination:

| Approved by Exempt Review, category # | ■ | Approved by Expedited Review, category # □ |
| Approved by Administrative Review |   |
| Full IRB Determination |   |
| Approved | □ |
| Conditional Approval (see email) - IRB Chair Signature/Date: |   |
| Conditions Met |   |
| Resubmit Proposal (see email) |   |
| Disapproved (see email) |   |
| Risk level: Minimal |   |

Final Approval by IRB Chair: [Signature] Date: 9/6/2022 Expires: N/A
Appendix C

IRB Amendment-2

Project Title: Women’s Experience Having an Infant in the NICU
Principal Investigator: Molly Murphy
Title: Doctoral Student
Signature:
Email address: molly2.murphy@umontana.edu
Work Phone: 406-370-6696
Department: Counseling
Office Location: Phyllis J. Washington College of Education and Human Services
Faculty Supervisor (if student project): Kirsten Murray
Department: Counseling
Work Phone: 406-370-6696
Email: Kirsten.murray@mso.umt.edu

Due to the health risks for this vulnerable population and the rise in Covid, I am applying to amend interviews to be in-person or remote via the zoom platform.

The researcher will conduct interviews in a private setting, and participants will be invited to participate in interviews in a private space. Participants will be asked to mail, scan or send a photograph of signed informed consent to participate on zoom interviews. Recordings will be stored on a password protected server.

I am also requesting a recruitment process change which includes: distributing the recruitment flyer via a closed group, social media posts and flyer distribution through points of contact including doctoral research groups, and NICU points of contact.

IRB Determination:

Approved by Exempt Review, category #
Approved by Expedited Review, category #
Approved by Administrative Review
Full IRB Determination
Approved
Conditional Approval (see email) - IRB Chair Signature/Date: __________________________
Conditions Met
Resubmit Proposal (see email)
Disapproved (see email)
Risk level: ____________

Final Approval by IRB Chair: __________________________ Date: 9/12/22 Expires: N/A
Appendix D

**Figure 1**

*Conceptual Map of Women’s Experiences in the NICU following first round analysis*

**Entering the NICU**
- Sudden and Unexpected
  - Disruption of Pregnancy
  - Entering Birth Alone
- Loss of a Dream
- New NICU Motherhood

**The Forgotten Mother**
- Overriding the Mother Role
- Detached and Dismissive Staff Responses
  - Role Rigidity
    - Emotional Handoff
- Infrastructure Collapse
  - Physical
  - Staff Challenges
- Frustration with System Communication
  - NICU Prep while Pregnant
  - Communication of Treatment Plans and Changes

**The Juggling Act**
- Logistical Tasks
  - Self-Sacrifice
    - Ignoring Physical Needs to Care for Infant
  - Work & Finances
  - Schedules
- Mental and Emotional Tasks
  - Maintaining Proximity to Infant
    - Fear of Being Unknown/Detached
    - Pain of Being Away from Infant
  - Alone
    - On My Own
    - Physical Space
    - COVID as a Complication
  - Nonlinear Medical Progress
    - Pregnancy
    - NICU
Women’s Journey Through the NICU

- Trauma with Infant’s Struggle

The Deep Dark Battle
- Lonely
  - Isolated
  - Emotionally Alone
- The Pervasiveness of Death
- Good Mom/Bad Mom Dichotomy
  - Good Moms pump and Produce Milk
  - Good Moms Spend all of their Time Present
  - Good Moms are Selfless
  - Good Moms Don’t Ask for Help
  - Other Moms
- Guilt
- Failure
  - I’m the Failed Vessel
  - Helplessness
- Shame
- Despair and Hopelessness
  - Desperate to Get Home
  - Personal Despair

Escaping the Spiral
- Avoidance and Distraction
- Family
- Social and Online
- Attuned Care
  - Staff Support for Relational Health Between Mother and Baby
  - Trust in the Medical Support
- Counseling
- Mom Pride
- Spirituality
  - Making Meaning
  - Spirituality

Post Discharge Experience
- Post-Discharge Anxiety
- Post-Discharge Reflections
- Post-Discharge Experiences to Explore Further

Note. This image depicts the conceptual map of Women’s experience after first-round interviews. The six emergent themes are unbulleted and in bold. Subcategories and properties fall below these themes consecutively.
Appendix E

Figure 2

The Juggling Act

The Pervasiveness of Death

Escaping the Spiral

Post-Discharge - Integrating the Deep Dark Battle

Figure 2

Conceptual Map of Women’s Experiences in the NICU

Note. This model shows the process that women move through as they experience being in the NICU with their infants. They begin with a sudden Entry into the NICU. They experience being bypassed and overlooked in The Forgotten Mother. Women are faced with tasks of The Juggling Act in which they manage external Logistical, and Mental and Emotional Tasks. As women face The Pervasiveness of Death that the NICU holds around them, they begin to look inward. Next, women moving into the internal downward spiral of the Deep Dark Battle. Women use supports to move out of this internal space and then experience Post-Discharge integration of their experiences while in the NICU. The arrows show the movement through process of the phenomenology.
Results of Women’s Experiences in the NICU

Note. This model shows the process that women move through as they experience being in the NICU with their infants. They begin with a sudden Entry into the NICU. They experience being bypassed and overlooked in The Forgotten Mother. Women are faced with tasks of The Juggling Act in which they manage external Logistical, and Mental and Emotional Tasks. As women face The Pervasiveness of Death that the NICU holds around them, they begin to look inward. Next, women moving into the internal downward spiral of the Deep Dark Battle. Women use supports to move out of this internal space and then experience Post-Discharge integration of their experiences while in the NICU. The arrows show the movement through process of the phenomenology.
Note. The Juggling Act has two subcategories, Logistical Tasks and Mental and Emotional Tasks that women are faced with managing. Logistical Tasks include Self-Sacrifice, Work & Finances, and Schedules. Mental and Emotional Tasks include: Maintaining Proximity to Infant, Alone, and Nonlinear Medical Progress.
Appendix H

Figure 4

*The Deep Dark Battle*

Note. This image depicts the internal Deep Dark Battle that women navigated within themselves. The Downward spiral indicates the deep recesses of emotion that women experienced, ending in Despair and Hopeless at the bottom of the spiral.
Appendix I

Figure 5

*Escaping the Spiral*

Note. This image shows the different supports that women used as a way of Escaping the Spiral of the Deep Dark Battle. The coping strategies and support mentioned here are in no particular order and are repeated as a way to indicate that any of these strategies may have been used throughout their processes.
Appendix J

Member Check Email Narrative

1. **Entering the NICU** emerged as the theme women identified as the starting point into this process and event. Participants offered their experience of suddenly and unexpectedly delivering their infants and being taken to the NICU. They discussed their internal experience of grieving lost moment with their infant, and then quickly having to learn and adjust to being a NICU mom.

2. The next theme that women identified in their experience of the NICU is **The Forgotten Mother**. This theme is where participants expressed being bypassed or overlooked both in their maternal role, and personally. The women in this study shared about their need to be cared for emotionally, physically, and mentally. Participants articulated many ways the bypass of these needs surfaced. Women explained their sense that the staff’s main focus was to treat and help their infants survive, and not attend to the mothers’ emotional or personal needs.

3. The **Juggling Act** is about the many “balls in the air”, tasks that women had to manage during their infants stay in the NICU. This theme is about *doing*, rather than *feeling*. These balls that women juggled were a way to keep their focus outward rather than having to look inward. By focusing on what needed to be managed there was a comfortable distancing created from having to address their own internal emotional experiences. Two main area’s were identified in the Juggling Act. The first subcategory is the **Logistical Tasks** that women had to maintain. These included self-sacrifice (putting themselves second to baby), work and finances, and the logistics of scheduling. The second aspect of the Juggling Act is the **Mental and Emotional Tasks** that women were handed as they navigated the NICU. These include the task of managing their emotions around maintaining proximity to their infant, being alone for long hours throughout the day, and enduring the nonlinear medical progress of their infant.

4. The **Pervasiveness of Death** theme developed fully after round-two interviews. In round one interviews all of the participants hinted at the nature of the NICU being emotionally heavy and frightening due to the possibility of death. However, no one named their fear or experiences with death. In round-two interviews I asked deliberately and directly about the impacts of the possibility of death for their own infant, as well as regarding the babies surrounding them. Participants engaged in sharing their deep worry and fears about this. They shared about the emotional distress they felt that knowing infants were dying. They also described feeling guilt and suffering for other mothers around them.

5. **The Deep Dark Battle** is the internal emotional downward spiral that comprised the core of women’s experiences in the NICU. All of the participants identified feeling aspects of
isolation, and being in an internal battle with their own feelings of guilt, failure, and helplessness. The spiral inward is comprised of subcategories of loneliness and isolation, “Good mom/Bad mom Dichotomy”, guilt, and in the deepest aspect of the experience, a sense of personal failure, shame, and even despair and hopelessness.

6. **Escaping the Spiral** The path to relief from the deep internal spiral women endured, was defined by multiple avenues of supports and coping. Women engaged in these skills to help themselves escape the emotional depths of the Deep Dark Battle. The subcategories of this theme include: Avoidance and Distraction, Family, Social and Online, Attuned Care, Counseling, Mom Pride, and Spiritual.

7. **Post-Discharge – Integrating the Deep Dark Battle** Round one interviews gave clarity that women experienced their post-discharge journey’s as a continuation of their NICU experience. Although it was apparent in first round-interviews that women were having high levels of anxiety post-discharge there were aspects of this experience that needed to be further explored with round-two interviews. The data from round-two interviews added significant clarity to the ways that women experienced this continuation as the next step in integration of the Deep Dark Battle. This is where women began to explore and unpack their deep internal emotions of the experience. Women identified subcategories of this experience as both challenging and wrought with emotional work, and with reflections which offered support to future NICU moms. Post Discharge Trauma, Continuation of Guilt, Continued Medical Complications, Reflections of Pride, Longing for Understanding and Connection, Finding Meaning, and Messages to Future NICU Moms.

Member Check Questions:

8. Is there anything about the diagram or description that is especially resonating with you?
9. Is there anything I got wrong?
10. Is there anything that needs to be added?
11. Is there anything that needs to be changed or removed?
12. What are your overall impressions?

References


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